HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION

Patient and Public Involvement in Health and Social Care

ANNUAL REPORT AND FINANCIAL STATEMENT

For the year ended 31 December 2015

Healthwatch and Public Involvement Association
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HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION

Patient and Public Involvement in Health and Social Care

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Special Thanks

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

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HAPIA STEERING GROUP MEMBERS 2015 AND THEIR PORTFOLIOS

RUTH MARSDEN Yorkshire and Humberside	Information Communications Trustee, Vice Chair
ANITA HIGHAM South East	Integrated Care for Older Adults Care of Young People with MH Problems Parliamentary Briefings
ELLI PANG South West	General Practice
ELSIE GAYLE West Midlands	Maternity, Obstetrics Patient and Public Voice Patient Safety Trustee (from 4th October 2015)
CATH GLEESON North West	Quality improvement in nursing Long Term Conditions Rural Health Young People's Health
JOHN LARKIN	Company Secretary Trustee
LEN ROBERTS South East	Briefings and Lobbying
MARY LEDGARD East of England	Rural Healthwatch
MALCOLM ALEXANDER London	Patient Safety, Mental Health Medical Revalidation Trustee, Chair
MICHAEL ENGLISH London	Parliamentary Advisor, Trustee (until 4th October 2015) Hon. President (from 4th October 2015)

REPORT AND FINANCIAL STATEMENT FOR THE YEAR ENDED 31st DECEMBER 2015

The Trustees have pleasure in presenting their Report and Financial Statement for the year ended 31 December 2015.

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 (appointed 4 October 2015, re-elected 27 November 2015)
- John Larkin (re-elected 27 November 2015)
- Ruth Marsden
- Michael English (resigned 4 October 2015 to become Hon. President)

Healthwatch and Public Involvement Association (HAPIA) comprises 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 act 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.

VISION STATEMENT

Healthwatch and Public Involvement Association (HAPIA) is a registered Charity that aims to provide a national voice for Healthwatch, and to help build the capacity of HAPIA members to achieve change and improvement in health and social care services at local, regional and national levels.

HAPIA aspires to facilitate the involvement of all people in the determination of health and social care policy, especially those whose voices are not currently being heard.

HAPIA actively promotes diversity, inclusivity and equal opportunities in relation to the improvement of health and social care services.

MISSION STATEMENT

1. To provide a national voice for Healthwatch and Healthwatch members.
2. To promote public involvement that leads to real change and the ability to influence key decisions about how care services are planned and run.
3. To 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. To support the capacity of communities to be involved with and engage in consultations about changes to services, to influence key decisions about health and social services and hold service providers and commissioners and the Department of Health to account.
5. To promote open and transparent communication between communities across the country and the health service.
6. To promote accountability in the NHS and social care to patients and the public.
7. To support the involvement of people whose voices are not currently being heard, and to promote inclusivity, diversity and equal opportunities.

HAPIA MANIFESTO

- 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, for the benefit of the public, 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's ACHIEVEMENTS IN 2015

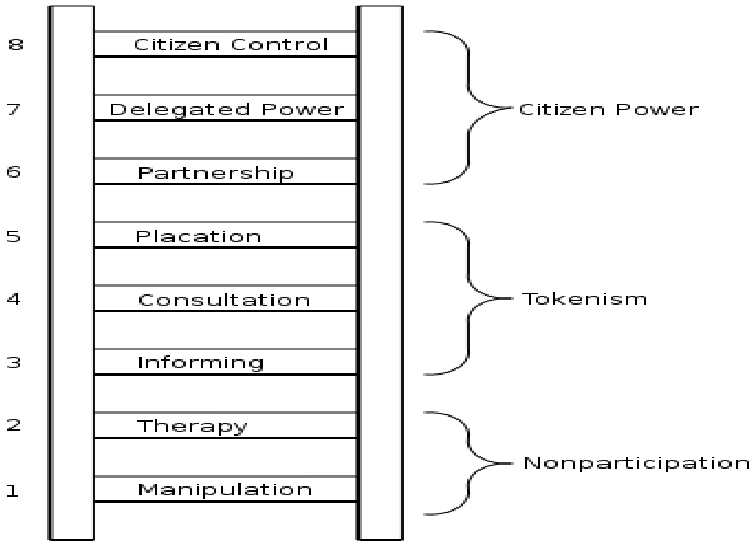
A. To Provide a National Voice for Healthwatch and Healthwatch Members.

HAPIA CONFERENCE - EIGHT STEPS TO POWER AND INFLUENCE ARNSTEIN'S LADDER TO CITIZEN EMPOWERMENT

HAPIA held a highly successful Annual Conference on Friday, 27th November 2015 at Friends Meeting House, Euston Road, London.

Sherry Arnstein's "A Ladder of Citizen Participation" is a key approach to developing user involvement and was the core theme in our 2015 annual conference. Arnstein was an urban redevelopment specialist who illustrated citizen participation in decision making with examples from the U.S. Department of Housing and Urban Development Modern Cities programme. The Ladder suggests a hierarchy of power and influence that leads ultimately to the disempowered having access to power and control in their communities. The different rungs on her Ladder relate directly to the degree to which citizens have attained decision making power with complete citizen control being defined as the highest point. The central focus is the redistribution of power that enables have-not citizens, presently excluded from the political and economic process, to be included in the future.

Emphasis on power focuses on developing an understanding between users, providers and policymakers as the means for users to influence service change. The model is most aspirational for users who feel they have no influence on services or for those who provide them and who want to change, transform and improve services. Arnstein's Ladder is at the core of our understanding on how to achieve the influence and power we need to challenge a system that may not be user focussed and is often in a state of change and sometimes crisis.



Speakers and topics included:

Ruth Marsden and Malcolm Alexander	**Joint Chairs**
Malcolm Alexander - Chair of HAPIA	The Arnstein Legacy
Ruth Marsden – Vice Chair of HAPIA	Challenging the system – lessons from the creation of PPI bodies
Elsie Gayle	Shared decision making in maternity care. Empowering relationships of mothers and midwives.
Anita Higham	Why is young people's mental ill-health a growing 21st century issue?
Mary Ledgard	Public engagement in a large rural area.
Polly Healy	What power and influence do Patient Participation Groups have on primary care? A case study – Sunbury Health Centre
Malcolm Alexander	The Tuberculosis Epidemic in England.

The **ANNUAL REPORT** for 2014 was presented to the Conference.
www.hapia2013.org/uploads/6/6/0/6/6606397/annual_report-hapia-final-2014_copy.pdf

The **CONFERENCE** reports and presentations can be seen at:
http://www.hapia2013.org/2015---agm.html

DEVELOPING POWERFUL AND EFFECTIVE HEALTHWATCH

We have made a request to the parliamentary Health Committee to review the development of LHW. This is based on our concern that over the past 15 years we have had four models of public involvement in healthcare, and that in each case the model, though essentially the same in terms of role, has been weakened in terms of influence and capacity to represent the public and influence providers and commissioners. Lack of key information about access to complaints data is central to our concern.

Although the current HW model has significant strengths in relation to its role in the Health and Wellbeing Board and the support of the national body Healthwatch England, there are many parts of the country where it is not meeting local people's needs, because of inadequate funding, in consequence of the government's decision not to 'ring fence' LHW budgets as well as the separation of IAS and LHW functions.

We also advised the Health Committee about the claim by HWE that £10m has 'disappeared' from the intended allocation for LHW and we highlighted our own report on the issue of funding entitled: The Funding of Local Healthwatch 2013-2016 which demonstrates the massive cuts in funding for some local Healthwatch bodies.

www.nalm2010.org.uk/uploads/6/6/0/6/6606397/hapia-august_13-2013-final-v1-3.pdf

We told the Health Committee that Healthwatch organisations must be an effective and powerful voice for their local communities. We believe an inquiry would ensure that the strengths and weaknesses of LHW are examined in detail with appropriate recommendations made to government. We advised the Health Committee to examine the following issues in relation to Local Healthwatch:

1) Absence of a role for LHW in relation to complaints advocacy
2) Funding of LHW
3) Independence and accountability of LHW
4) Significant variations in capacity and performance
5) Effectiveness in terms of influencing providers and commissioners of health and social care

6) Influence exercised by LHW in HWBBs
7) Impact of LHW in relation to the implementation of recommendations from the Francis and Berwick Reports
8) Indemnity for LHW volunteers when inspecting health and social care services.

We wrote to Sarah Wollaston MP, Chair of the Health Committee, on a number of occasions requesting an inquiry into the effectiveness of Healthwatch but although her Committee did publish the statement above an inquiry was never established.

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

HAPIA has explored the problems faced by rural Healthwatches when gathering the views of people across large rural areas. We identified the following issues:

- Ensuring representative samples of views from dispersed local populations, and resisting the temptation to go for the easy options.
- Promoting equality of access to services across the whole Healthwatch area.
- Building up a knowledge base of local services and working with local community groups and organisations, to fulfil Healthwatch’s information, signposting and advocacy role.
- Keeping track of proposed cuts, closures and reconfigurations across the whole of the area (especially at a time of funding cuts) and promoting effective and inclusive public consultation.
- Making the most effective use of members’ and volunteers’ contributions towards Healthwatch as a highly reliable and valid source of patient and public experiences of health and social care services.
- Setting realistic priorities and goals given the large and diverse range of services that need to be monitored – operating strategically with good action plans and outcomes.
- Monitoring the safety and quality of services provided by a large number of providers, some of which may be very local and small.

We concluded that whilst approaches to delivering effective local Healthwatch in a rural area will vary, they must include putting in place a communications network that reaches out to as many areas as possible. This can be accomplished by deploying volunteers, supported with appropriate training, mentoring, and guidance on their specific roles in supporting Healthwatch's local strategy. Of great importance is the development of partnerships including 'partnerships of partnerships', to share knowledge and intelligence, avoid duplication and make the best use of scarce resources.

Keeping the independent focus of Healthwatch is essential when working with other organisations both statutory and voluntary. Being realistic and honest about what can be delivered within what timescale - rather than raising expectations and failing to deliver -will ensure the credibility of rural Healthwatch. Above all, local Healthwatch organisations need to monitor and publicise proposals and plans for national, regional and local changes to the delivery of health and care that could affect the safety and quality of service for the public in their area.

CHAMPIONING THE PEOPLE'S VOICE
Reflections and discussion on Healthwatch

Our aspirations for effective and powerful patient and public involvement in health and social care are identified in this discussion piece, particularly with regard to the duties of central and local government to support the development of successful local Healthwatch organisations. Our aspirations and concerns are presented through a series of questions:

A) Do central government and local authorities genuinely want to champion a powerful people's voice in health and social care? Does government really want to promote 'patient power' or are the series of PPI organisations established since 2003 – Patients' Forums, LINks and Healthwatch, merely a democratic sop? Were the hopes and expectations placed in the Health and Social Care Act 2012, which created 150 Local Healthwatch (LHWs), undermined and shattered by the creation of HW bodies not focussed on the needs of the most deprived communities and individuals and insufficiently funded?

B) Was the Department of Health (DH) fully committed to the development of successful LHWs in 2012, but defeated by the Treasury on the funding issue, as demonstrated by the DH's unwillingness to 'ring-fence' LHW funding? The 'Locality Bill' was at that time proceeding through Parliament and 'localism' ensured that most LHWs have been massively underfunded, because each local authority can decide on the level of funding for their LHW.

C) Why was the DH not fully committed to a Healthwatch England (HWE) that led, supported and funded LHW? Why did the DH not allow every LHW to be fully accountable to its local community, rather than to its local authority, which it both monitors and receives its funds from. Why create such absurd conflicts of interests?

D) Why has HWE been placed under the umbrella and control of the CQC – one of the bodies it monitors? Another absurd conflict of interests, which prevents HWE from having the authority and control it needs to speak to government on behalf of the population of England that it is intended to serve.

E) Why have many Local Authority ‘Health and Well-Being Boards’ been so weak and so ineffective? They were intended by the Health and Social Care Act 2012 to strengthen accountability and joint working between local government, the NHS and LHW to promote integrated health and care services. They also provided the prospect of closer work with public health and education. Were elected Councillors and Chief Executives never fully committed to the opportunity to create integrated care and therefore failed to grasp the potential power of HWBBs to bring together health care, public health and social care?

The HWBB model was designed to ensure the production of local strategic plans for the improvement of the health and well-being of the local population. Why have many HWBBs failed to comprehend the potential force of an effective "Joint Strategic Needs Assessment"? and why do many Councillors fail to engage openly and courageously with this opportunity for effective planning of NHS, social care and other local services?

F) Why have HWBBs not fought harder to increase local democratic legitimacy in the commissioning of health and care services, and why has the potential power of Local Healthwatch to ensure patients and the public have a direct say in the strategic planning to meet the health and care needs of their area failed to materialise?

G) In the new world of "Sustainability and Transformation Planning" (STP), in which LHWs have, in some cases, been participants, is there a glimmer of hope that the "voice of the people" (patients, carers and the public), via its LHW champion, might be heard more loudly, or will the new STPs make NHS and social care planning even more remote from the people? www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/stp/

H) Why has leadership of the Secretaries of State for education, health and Local Government been lacking in relation to the development of integrated services, e.g. they do not seem fully to comprehend their duty to provide effective support and care for young vulnerable people, especially those with mental health problems. Stories of children travelling hundreds of miles for a mental health bed are common. There is also a need and a duty to young people, as they proceed into adulthood, to ensure they have the knowledge and confidence to demand their rights to the best possible physical health, mental health, social care and public health. Good practice on this issue has however recently been evidenced from Healthwatch Oxfordshire, which has been working successfully with students at Icknield School in Oxfordshire.

I) Why do so many socially and economically deprived people fail to get effective care; including the frail elderly, mothers of new born babies, homeless people and victims of austerity? Why do they sometimes experience a lack of respect, dignity, compassion from service providers in primary and secondary care?

J) The provision of effective advocates to ensure access to accurate and detailed advice and integrated planning, when people need complex care and treatment, is essential. A professionally competent ‘listening ear' is essential through an organisation with the ability to ensure that the right care is provided first time and every time. Who better to champion this need if not the Local Healthwatch? But this will require much greater levels of funding and access to the services of LHW for vastly greater numbers of service users. At the moment LHW is hardly known in many communities. Continuous public advertising of LHW is essential.

K) We believe that HAPIA’s robust alertness, relentless activity, networking skills and growing profile across and beyond the voluntary sector can open the eyes and ears of central government to these questions and find solutions through effective work and collaboration with local Healthwatch, the wider voluntary sector and Healthwatch England.

C. To promote 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.

THE 'SUCCESS REGIME'– CONSULTING THE PUBLIC

Our members have vigorously campaigned for the CCG's 'Success Regime' in Devon to consult and involve local people actively in decisions regarding the reconfiguration of services and the future of NHS community hospitals. The Devon Health and Social Care Forum and other community organisations have argued strongly for patients and the public to be included actively and fully in discussions on proposals for significant and substantial changes to the CCG's strategies, procurement policies and commissioning of services. There has also been considerable concern that Price Waterhouse Cooper, which was brought in to scrutinise the role of the CCG, largely omitted to seek the views of local people or establish any reasonable public consultation. HAPIA has assisted by preparing a detailed statement on the duties of the NHS to consult and as a result members were offered a meeting to discuss this issue with NHS England (South).

NHS Improvement claims that the Success Regime seeks to address deep-rooted and systemic issues that previous interventions have not tackled across health and care services, and to provide local organisations with the means and opportunity to work together to improve services for patients. Local communities are awaiting evidence that the Success Regime intends to include the public, communities and patients in decision making and that it will ensure that all major decisions are made with full public consultation.

The rights of communities to participate in the determination of what services are provided in their area, including design, access, quality and safety of services, are described in the Health and Social Care Act 2012: s26, 14Z2 and include the following duties:

> (2) CCGs must make arrangements to secure that individuals to whom the services are being or may be provided are involved (whether by being consulted or provided with information or in other ways) —

(a) in the planning of the commissioning arrangements
(b) in the development and consideration of proposals for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals

NHS England's 'Four Tests' procedure introduced by the Department of Health in 2010 have also been largely disregarded. These tests required that, when any significant changes are proposed to health services, the following criteria shall apply:

1. Support from GP commissioners for any major change is essential;
2. Arrangements for public and patient engagement, including local authorities, should be further strengthened;
3. Clarity about the clinical evidence base underpinning proposals must be provided;
4. Proposals should take into account the need to develop greater patient choice.

On January 9th 2013 David Cameron as Prime Minister stated:
"What the Government and I specifically promised was that there should be no closures or reorganisations unless they had support from the GP commissioners, unless there was proper public and patient engagement, and unless there was an evidence base. Let me be absolutely clear: unlike under the last Government when these closures and changes were imposed in a top-down way, if they do not meet those criteria, they will not happen".

NHSE has unfortunately ignored its own 'Four Tests', as well as disregarding the then Prime Minister's promise, its statutory duty to consult, and case law. Our members have demanded that NHSE fully and actively involve and consult community bodies, Healthwatch, patients, service users, carers and the public in any plans to make substantial or significant changes to services in Devon, and in the process of making such decisions through the CCGs.

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 the court agreed that the decision-maker's discretion is not unbounded and cannot retrospectively consult on a decision already made, because the outcome of such a consultation is pre-determined and the process pointless. 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.

EAST RIDING OF YORKSHIRE HEALTHWATCH

Our members have campaigned actively to make Healthwatch East Riding the volunteer-friendly and genuinely inclusive organisation it had been at the beginning. They have challenged - via the local authority, Healthwatch England and the House of Lords - the highly questionable over-control exercised by Meeting New Horizons as a support organisation engaged by the local authority to support the development of Healthwatch East Riding of Yorkshire.

In September 2015, Richard Davies, the properly appointed Chair of the Healthwatch, spoke to the Health, Care and Wellbeing Overview and Scrutiny Sub-Committee and stressed how “successful implementation and delivery” of Healthwatch had initially been achieved, and that the positive feedback received from the regular monitoring meetings with Council Officers demonstrated that the Healthwatch was amongst the top 25% of best performing Healthwatches in the region. He described the six hardworking Directors, who lived within the East Riding, and their successful work for local people supported by the committed volunteers, who also lived in the East Riding, and who helped deliver the Healthwatch’s outstanding work. All of the Healthwatch Directors had nevertheless resigned in July 2015 because they felt marginalised and disempowered by the unilateral actions taken without consultation by Meeting New Horizons to change the governance structure and operation of the Healthwatch. Meeting New Horizons was publicly funded to support the East Riding Healthwatch, its Directors and the community, but had instead in effect usurped the role of the Directors and made themselves into the de facto Directors of Healthwatch. The original Directors were on record as stating that they had resigned because Meeting New Horizons had made it impossible for them to carry out governance roles to which they were appointed, and because Meeting New Horizons had undermined the Nolan Principles in relation to transparency, accountability and financial management. Meeting New Horizons had further ‘sacked’ all the volunteers who had questioned the unconstitutional takeover of Healthwatch by Meeting New Horizons.

Following the continuing concerns of all the marginalised volunteers, strenuous representations were made to meet with and explain these concerns to the East Riding of Yorkshire Council, but all of these representations were unfortunately rebuffed. A formal complaint was then made to ERYC, on the grounds that it had persistently declined to meet with and hear from its constituents, notwithstanding more than a dozen written requests for them to do so.

This formal complaint was also rejected by the Council, and the subsequent lodging of an appeal was similarly declined. Meanwhile, colleagues in the House of Lords asked questions in the House and met with the minister, Lord Prior, and Healthwatch England has continued to work with these volunteers through its Regional Manager to take forward their concerns. The sudden departure of Meeting New Horizons' CEO, who as a non-resident of the East Riding of Yorkshire had nevertheless put himself de facto on 'the Board' of LHW ERY together with the de facto appointment of others who did not live in the East Riding, may also have some bearing on the outcome.

CUMBRIA

Our members expressed their concerns amidst evidence of serious weaknesses in the performance and governance of Healthwatch Cumbria. The issues were raised with Cumbria County Council and the CEO of People First, offering a meeting to resolve the matters of concern, and to engage with representatives – and the board - of Healthwatch Cumbria and with People First for the same purpose. These overtures met with no response until Healthwatch Cumbria instead reacted by responding to criticisms of their performance through a solicitor who sought to develop vexatious and intimidatory aspersions against a HAPIA member. Neither Healthwatch Cumbria nor its solicitor was able or willing to substantiate any such allegations against our member, even though supporting evidence was invited and both the Healthwatch and its solicitor were reminded of their duty to act in accordance with the Nolan Principles of public engagement:

THE NOLAN PRINCIPLES

Selflessness: Holders of public office should act solely in terms of public interest.

Integrity: Holders of public office must avoid placing themselves under any obligation to people or organisations that might try inappropriately to influence them in their work. They should not act or take decisions in order to gain financial or other material benefits for themselves, their family, or their friends. They must declare and resolve any interests and relationships.

Objectivity: Holders of public office must act and take decisions impartially, fairly and on merit, using the best evidence and without discrimination or bias.

Accountability: Holders of public office are accountable to the public for their decisions and actions and must submit themselves to the scrutiny necessary to ensure this.

Openness: Holders of public office should act and take decisions in an open and transparent manner. Information should not be withheld from the public unless there are clear and lawful reasons for so doing.

Honesty: Holders of public office should be truthful.

Leadership: Holders of public office should exhibit these principles in their own behaviour. They should actively promote and robustly support the principles and be willing to challenge poor behaviour wherever it occurs.

Healthwatch Cumbria was also reminded of its duty to demonstrate due regard to Article 10 of the European Convention on Human Rights, which is embedded in the Human Rights Act 2010 and provides the right to freedom of expression and information, subject to certain restrictions that are "in accordance with law" and "necessary in a democratic society". This right includes the freedom to hold opinions, and to receive and impart information and ideas.

Article 10 – Freedom of expression

1. Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.

2. The exercise of these freedoms, since it carries with it duties and responsibilities, may be subject to such formalities, conditions, restrictions or penalties as are prescribed by law and are necessary in a democratic society, in the interests of national security, territorial integrity or public safety, for the prevention of disorder or crime, for the protection of health or morals, for the protection of the reputation or rights of others, for preventing the disclosure of information received in confidence, or for maintaining the authority and impartiality of the judiciary.

HAPIA met with Healthwatch England to discuss our concerns and they agreed to convey these concerns to Healthwatch Cumbria, but from whom no apology has since been forthcoming for the totally inappropriate attack on a HAPIA member who criticized the effectiveness of Healthwatch Cumbria. It is naturally of great public concern that a body set up under the Health and Social Care Act 2012 to enhance the public voice and public involvement in health and social care would ever choose to act contrarily in a unilateral endeavour to stifle or diminish the public voice.

PHASING OUT OF PMS CONTRACT FOR GPs – IMPACT ON PATIENTS

The phasing out of PMS [Personal Medical Services] contracts for GPs has greatly destabilised primary care provision in the East Riding of Yorkshire. PMS contracts were encouraged in 2004 by the government of the day, and GPs who opted for PMS contracts provided additional services and were resourced accordingly. These additional, quality-related services now default to secondary care, leaving desperately stretched hospitals and their emergency services all but overwhelmed. This makes an absurdity of the policy to keep care close to home and to keep people out of hospital, especially as East Riding hospitals already loom large amongst those hospitals in England responsible for the majority of A&E failures to meet the four hour target.

Funding cuts of £58,000 to PMS GP practices prevent them from providing about two dozen clinical services. This then creates an on cost to local hospitals of about £200,000. Neither the policy nor the finances make any sense. Further, patients now have to travel across the region to be part of the already back-logged queues at the hospitals. This scenario challenges and undermines the principle of 'fitting the service to the patient, not the patient to the service'.

Work is ongoing with NHS England through Sir Bruce Keogh [National Medical Director], Dr Mike Bewick, Ros Roughton, [Director of NHS Commissioning], and with the Medical Director, North Yorkshire & Humber Area Team to resolve this major problem. Further work has been undertaken through Lord Hunt of King Heath, and Lord Harris of Haringey, to challenge this blanket system which is causing so much harm to patients needing both primary and secondary care. There is also an almost total lack of meaningful patient and public involvement in these service changes.

Although the 'Dear Colleague' letters from NHS England clearly talk of the "impact on patient services" as a result of phasing out PMS contracts, there has been no airing to the public and service users of what the impact is likely to be and no opportunity for them to provide input or exercise choice. Such pivotal negotiations must include both the clinical voice and the public voice.

Lawyers have elsewhere threatened to take NHS England back to court if it cannot show it is taking steps to involve patients in primary care commissioning decisions. The law firm Leigh Day issued the warning after claiming NHS England had not responded to letters sent two weeks after a November 2015 High Court ruling, that NHS England had acted unlawfully. High Court judge Mr Justice Popplewell said NHS England was failing to comply with provisions of the NHS Act 2006, requiring patients to be involved in decisions. The ruling could have widespread implications requiring NHS England to ensure individual patients are consulted and involved in the "development and consideration" of decisions or changes to primary care, where they affect health services which those patients might use.

NHS England claimed that it had undertaken the necessary meetings with practices affected, but in reality the process has been one of imposition, not consultation. An apparent invitation for practices to put forward a case for the funding of services that they provide, over and above baseline services, caused practices to spend much time collating evidence to present their case, only to find every one of these representations dismissed.

NHS England and the CCG asserted that ‘the CCG in association with NHS England will ensure current funding supports patient services most effectively’, and gave an assurance that the removed PMS funding would be reinvested across primary care within the region, but the CCG then made a unilateral decision that the money would instead go to referrals.

Colleagues in the House of Lords enquired as to progress, Hansard source (Citation: HL Deb, 6 January 2015, c146W)

Lord Hunt of Kings Heath, Labour, 6th January 2015
To ask Her Majesty’s Government what assessment they have made of the impact of the withdrawal of Personal Medical Services (PMS) payments on practices with a large number of deprived patients.

Earl Howe, Conservative, 6th January 2015
The Department has made no such analysis. Area teams will work with PMS practices to assess the impact of any reduction in payments on its registered patients.

NHSE subsequently ran a workshop which was held in central London - ‘’Reshaping Primary Care - an opportunity to be involved’’ and ‘’ to look at what matters most to patients and carers in primary care’’. Attendees were to be made up of key professionals within primary care as well as a number of patients and carers. After an application was made and agreed for a HAPIA member to attend the workshop, an accompanying carer was then declined, with the result that attendance was not possible. Further robust representations for patient and public involvement were made with the local CCG who declined to meet with HAPIA on the grounds that its members were only ‘the public’, not professionals. The ongoing collaboration between the GPs and HAPIA in continuing pursuit of equitable and transparent behaviour from their CCG was only made possible by the GPs placing a HAPIA representative on contract with them as Responsible Officer for Patient Outcomes, thus ensuring that further patient and public involvement could not be denied. This work has continued successfully.

References:
-“What change local areas want to achieve to the model of care, in order to meet the needs and preferences of their local population” [Forward View into Action. Registering interest to join the new models of care programme]

Giles Wilmore, director for patient and public voice at NHS England, “working with patients and communities is fundamental to NHS transformation”. [http://www.networks.nhs.uk/networks/news/working-with-patients-and-communities-2013-the-key-to-nhs-transformation]

-“The emphasis is on empowering patients at the heart of the planning requirements.”[http://www.england.nhs.uk/wp-content/uploads/2015/01/pb-mins-171214.pdf]

-“The need for a significant shift in ways of working to ensure that citizens were involved in commissioning decisions”.[http://www.england.nhs.uk/wp-content/uploads/2015/01/pb-mins-171214.pdf]

-“The NHS Five Year Forward View sets out how the health service needs to change and argues for a more engaged relationship with patients and communities” http://www.england.nhs.uk/wp-content/uploads/2015/01/item3-board-290115.pdf]

D. To promote open and transparent communication between communities across the country, and the health service.

REVALIDATION (LICENSING) OF DOCTORS

HAPIA has asked the GMC, at meetings of the English Revalidation Board, to put the name of each doctor’s Responsible Officer on the GMC website so that it is easier to ensure that every doctor is being properly connected to the revalidations system. This is particularly important for locums and doctors who are not in conventional systems of practice, e.g. those in the private sector. **The GMC responded positively to this request after the matter had been raised and discussed on several occasions with the support of other key bodies on the Revalidation Board.**

The licensing of doctors on a five-year cycle started in 2012, and by 2016 all doctors practising in the UK are due to be annually appraised and revalidated, with the process due to be repeated every five years. Each doctor has a Responsible Officer who is usually the senior doctor in the hospital where they work - or for GPs a doctor working for the regional branch of NHS England.

HAPIA has a seat on the English Revalidation Implementation Board (ERIB) that meets quarterly to review progress with revalidation.

- Are all doctors being appraised annually?
- Are all doctors connected to a Responsible Officer?
- How are comments from patients and colleagues collected for discussion during Annual Appraisals?

HAPIA has produced a leaflet about Revalidation that can be adapted for any location where doctors work. The leaflet has been adapted for each London hospital. More information and leaflets are available on the HAPIA website:
http://www.revalidatingdoctors.net

Although most doctors are connected with the revalidation system, concerns remain about the appraisal of locums who move jobs frequently and the appraisal of doctors who work for private clinics and a wide range of other bodies. NHS England acknowledges that “there remain an ever decreasing small number of doctors still practising that have not fully engaged with revalidation”, but they do not have any definitive list to highlight organisations where doctors are not connected to an RO.

HAPIA will continue to press NHS England and the GMC to ensure that doctors who are locums and those working for the private sector, or providing medical advice to non-medical organisations, are fully connected to the revalidation system and therefore practising safely and subject to regular review by colleagues.

HAPIA has been active in pressing for more rigorous procedures to ensure that, where there have been complaints about locums or where they have been involved in poor practice, information about the doctor is relayed to their Responsible Officer and Appraiser. Developing effective patient involvement in Revalidation should be a major priority, but at the moment all that is required are 30 comments from patients within a 5 year period.

WORKING WITH NHS ENGLAND - NHS England Expert Patient Safety Groups

HAPIA has actively participated in one of the NHS England expert groups on patient safety dealing with mental health. The intention of the group is to bring together people with a range of skills and experience to focus on what can be done to improve the safety of services for patients receiving care for a mental health problem.

The objectives of the Patient Safety Groups are nevertheless unclear and they do not generally influence policy. HAPIA is working with other community representatives to steer the groups to make them more effective so that they have more impact on the safety of local mental health services. NHS Improvement is due to take responsibility for the Groups in 2016.

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

HEALTHWATCH AND DETENTION CENTRES

We responded to a CQC Consultation entitled “Our approach to regulating health and social care in prisons and young offender institutions, and health care in immigration removal centres”.

We made the following points about inspection, monitoring based on inclusion, and the needs of people who are detained in Immigration Removal Centres.

- When IRC detainees are seeking asylum, they are not actually deemed to have committed any crime, yet they are detained as if they had been found guilty of a criminal offence. The conditions of detention are therefore likely to have a profound impact on their mental health, particularly if they have sustained unlawful detention and human rights abuses in their country of origin.

- The Consultation document fails to mention the critical role of Local Healthwatch and Healthwatch England, the two bodies established by Parliament, through the Health and Social Care Act 2012, to monitor health and social care service for all services users in England.

- The CQC is aware that HAPIA's request to Theresa May, then Home Secretary, to confirm Healthwatch's role in the monitoring of IRCs received a positive response. Guidance is therefore needed to raise awareness with LHW about the use of their statutory powers in meeting with people in IRCs to obtain details of their experiences of care services.

- The Inspection Team must ensure that detainees fully understand the role of the CQC, HMIP and Healthwatch in advance of their visits, and information must be produced in the first language of detainees. This process must be rigorous and carried out sensitively.

- Full details of Inspection Team members - including names and background details - must be provided to detainees during the CQC visit to IRC.

- At the end of inspection it is essential to invite LHW, Medical Justice and the IMB to the final CQC Summit to be able to comment on the draft report and the findings.

- Providing information freely to the Inspection Team is a major challenge for most detainees because they do not know whether the Inspectorate is simply an information source for the Home Office, nor whether any confidential information they provide will be used by the Home Office to cause them harm.

- Interviewing former detainees of the IRC who have been visited is an essential way of gathering data about the quality of care provided to detainees. Medical Justice has access to many former detainees who could be interviewed without loss of confidentiality.

- The Inspection Team should ensure that due regard has been paid to the need to provide independent complaints advocacy to detainees in relation to complaints they may wish to make about health care services.

COMPLAINT TO NHSE OVER THEIR FAILURE TO CONSULT ON KPIs

KPIs are key performance indicators, which are used to develop higher quality services. HAPIA made a formal complaint to NHSE concerning its failure to carry out a legal consultation on the development of KPIs in detention centres. We focussed particularly on Campsfield Immigration Removal Centre in Oxfordshire, and collaborated closely with the charity Medical Justice in this work.

Our complaint was directed against Sue Staddon, Head of Health and Justice Commissioning for NHS England South (South Central), because she had persistently refused to allow any consultation on the KPIs.

We reminded NHSE of the commitment made to HAPIA and Medical Justice on NHSE on June 23rd 2015 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 also told that "There is a review of the breadth of the participation of existing patient and patient advocacy groups within NHS England’s ongoing stakeholder consultation activity for IRC service specification development”. NHSE said that this approach would “ensure that Medical Justice and HAPIA can join those bodies that are already taking part in this activity going forward". NHSE also told us that "All parties proactively commit to seek out additional ways to engage in collegiate joint working going forward".

We explained that NHSE's failure to involve us adequately and appropriately in the development of KPIs has potentially serious implications for people detained in IRCs and also for NHSE. We stated that NHSE has a duty to consult and that it should have taken place when the KPIs were being developed to enable Medical Justice, HAPIA and service users to exercise influence. We told NHSE that they must be able to produce evidence that views are genuinely taken into account and we asked to meet with Sue Staddon to discuss this issue but she declined.

The response we eventually received from NHSE was a confirmation of their decision to refuse public consultation. We are therefore pursuing the matter with the Chief Executive of NHSE and with the Ombudsman.

F. To promote accountability in the NHS and social care to patients and the public.

DEVELOPING EFFECTIVE AND POWERFUL COMPLAINTS SYSTEMS

HAPIA submitted evidence to the Health Committee investigation into Complaints and Raising Concerns:
www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/350/350.pdf

Handling of complaints made by patients and families about care received in the health and care sectors, including both primary and secondary care providers.

We made the following key points:

1) The quality of response letters to complaints is generally improving, but the outcome of complaints - in terms of what has been learnt by staff, how the organisation has changed the way it does things, and how this is demonstrated to the complainant - continues to be weak. Complainants usually and understandably want to see organisational change, improved services, changes in the ways that staff respond to them, better information etc., but in practice these changes often do not occur when the investigation is complete, or if they do happen they are not visible to

the complainant. It would be of immense value if after six months of the complaint having been submitted, the complainant is advised of what has been done as a result of the complaint, what has changed, and providing some evidence that the changes are enduring.

2) Most people who make complaints do so either when they are extremely angry or because on reflection they really want to see change occur in the organisation. The best hospitals value complaints; demonstrate a good, sensitive, inclusive, investigation process; carry out the investigation quickly; meet with the complainant if appropriate; and ensure that the response is provided within a reasonable time frame. In practice this occurs relatively rarely. Good practice provides an opportunity for the person complained about to meet with the complainant so that, if necessary, a sincere apology can be given face to face – such an approach can have a profound impact on the complainant, transforming relationships between patients, clinicians and the hospital, and can help transform a hospital's culture.

3) With regard to primary care complaints, the confusion created by the changes to primary care commissioning has resulted in disarray. NHS England takes no responsibility for the dysfunctional situation it has created. Under the present system if a complaint is made to a GP, dentist, optician or pharmacist directly and the complainant is unhappy with the response, the only appeal is to the Health Service Ombudsman, who in practice is usually unlikely to take much action. If the complainant appeals to the GP Commissioner – NHS England - this will generally result in a refusal to examine the complaint, even though it is they who commission the service. If however the complaint is sent first to NHS England, they will deal with it and carry out a brief investigation. Members of the public are ill-informed about this opaque and illogical way of running a complaints system. The investigation of primary care complaints has now travelled as far as it possibly can away from responding appropriately and adequately to complaints.

Support for patients, the public and staff who wish to make complaints or raise concerns

Local Healthwatch has no specific role with respect to complaints advocacy, except where the local authority has decided to include the Independent Advocacy Service (IAS) within the remit of Local Healthwatch. In most localities the IAS role is run separately from the Local Healthwatch. The only statutory activity available to Local Healthwatch with respect to IAS is the role of signposting people to IAS. As LHW remains little known to the public at large and is rarely visible, it is unfortunately highly unlikely that people wishing to make complaints will be signposted by LHW. The separation of LHW from the IAS is in our view irrational and inefficient. Over the past 12 years the separation of public involvement from complaints advocacy has resulted in the public involvement organisations (Patients' Forums and Local Involvement Networks-LINks) being able to access little or no information about the most serious complaints submitted to NHS bodies.

Healthwatch should be able to use complaints as a means of rapid intervention. Hence, if a complaint were made to Healthwatch about poor care on a ward, there would be the opportunity to carry out an immediate inspection of the ward, talk to the Chief Executive and produce a report on the findings.

The current separation of health care from social care complaints is lacking in practicality even though in practice robust attempts are being made to integrate health and social care; but if a patient or family wish to make a complaint about both services they will need to make two complaints to different bodies and perhaps require two advocates from different organisations to support them.

Handling of concerns raised by staff about care given in the health and care sectors

The Regulations currently do not enable staff members to make complaints about patient care. In a recent example, a nurse based in a hospice discovered that a patient had been denied transport to the hospice, because the ambulance service did not have the resources to transport the patient for urgent care, but did not tell the nurse in good time. She could therefore not arrange appropriate alternative care. She complained to the ambulance provider, and although her complaint was dealt with informally, she was advised that the Regulations did not allow health workers to submit complaints against providers. These Regulations clearly need changing.

THE TUBERCULOSIS EPIDEMIC

Our report on the Tuberculosis epidemic demonstrates a deeply disturbing failure by NHS England and Public Health England to deal successfully with the spread of infection and the identification at an early stage of people with latent TB. We have highlighted the public health scandal that Newham in east London has the highest incidence of latent tuberculosis in the whole of Western Europe. Latent TB refers to an undiagnosed infection in early life that is contained and may become harmful and infectious in later life.

The Tuberculosis epidemic (TB) has hit London the hardest with about three thousand new cases each year. Sadly, treatment sometimes fails and the law on infectious diseases may hinder rather than help. Stigma, poverty, migration, homelessness and the interface with illegality are some of the key issues explored in our report, as well as the impact of antibiotic resistance on TB treatment and the risks associated with detention and deportation. The legal right to detain people who suffer from TB is a little known aspect of the infectious diseases Regulations. The UK's incidence of TB is about 8000 cases per annum (compared to 5000 cases in both France and Germany).

About 9% of TB patients in London have a drug resistant strain, and 2% have multi-drug resistance (MDR). Annual figures of TB incidence are rising in Brent (279), Ealing (213) and Newham (335) whilst falling in Hackney (86) and Camden (45). A third of London's TB patients are treated in hospital, and since 2010, eleven people have been treated in detention under the Health Protection Regulations (DH 2010). In the community DOT (Directly Observed Treatment) is the most common form of treatment and provides assurance that patients are taking their medication (WHO 2006).

Public Health England (PHE 2014) produces data about rates of infection, ethnicity, antimicrobial resistance, deaths from TB and failure to complete treatment, but nothing is available about patients who are detained in hospital or Immigration Removal Centres (IRCs) or deported during treatment. There is virtually no information for patients in the NHS regarding treatment or TB detention. The TB Action Group charity attempts to break the stigma of TB by highlighting patients' stories and produces leaflets funded by the NHS, but these are not distributed to hospital PALS and none of the bodies we contacted had seen the wide range of leaflets produced by the TB Action Group.

The World Health Organisation (WHO) called on governments to tackle the TB crisis by 2015 – the year in which PHE finally produced its TB strategy (WHO 1994). Substantial resources and effective organisation are needed to deal with the epidemic – but London has 32 separate TB teams – whereas New York with one integrated team successfully tackled their 1990s epidemic.

Public health law may have a role in relation to the TB epidemic and is examined in our report to consider whether it is humane, and what impact it has on patients' rights, social and economic harm and breaches of civil liberties. Our report explores the tension between the WHO approach - "Despite the gravity of the global problem, it is within our grasp to reverse the epidemic" (WHO 2010) - and the UK approach which has failed to tackle the epidemic and deports partially treated TB patients who may return to the country they fled from, without resources for continuing treatment – despite the claim that the WHO will step in and fix the treatment gap. Our report also explores possible reform of UK law and policy to create a system for people with TB that protects their health, social and economic interests and simultaneously protects the interests of the wider community.

During the collection of data for this report, the frequent riposte to questions put to PHE and NHSE about policy on TB was “Why do you want to know?”. This reaction perhaps suggests anxiety about the very high incidence of TB in the UK. However, we also discovered many very passionate and committed clinicians working to eradicate the epidemic.

Incidence of TB

PHE has declared it will halve TB cases by the year 2018 (London TB Control Board, 2013). The UK performance is inadequate compared to other countries in Western Europe (WHO 2012). Current priorities for PHE include tackling latent TB and treating those who are homeless/socially deprived (PHE and NHSE 2015).

INCIDENCE OF TB IN THE UK AND LONDON

	New cases UK	New cases London	TB deaths - UK
2004	7594	2786	346
2005	8290	3098	362
2006	8314	2968	371
2007	8268	2824	300
2008	8495	2976	339
2009	8878	2989	302
2010	8398	2832	299
2011	8923	3059	256
2012	8729	2993	261
2013	7892	2591	280
Total	83,781		3,116

PHE (2014: Appendix 1)

CASES OF TB IN WESTERN EUROPE - 2006-2010 (WHO 2012)

Country	Rate (2006) Per 100,000	Cases	Rate (2010)	Cases	Annual Change 2006-10
UK	**13.8**	**8363**	**13.7**	**8483**	**-0.2**
Austria	11.0	906	8.2	688	-6.8
Belgium	10.6	1117	10.3	1115	-0.5
Denmark	7.1	387	6.5	359	-2.1
Finland	5.7	297	6.1	327	+3.4
France	8.4	5323	7.9	5116	-1.4
Germany	6.5	5378	5.3	4330	-5.0

Ireland	11.0	463	9.6	427	-3.3
Italy	7.7	4503	5.4	3249	-7.9
Netherlands	6.3	1031	6.5	1073	+0.9
Spain	18.3	8029	15.4	7089	-4.1
Sweden	5.5	497	7.2	675	+7.2
UK	13.8	8363	13.7	8483	-0.2

HAPIA'S RECOMMENDATIONS TO PUBLIC HEALTH ENGLAND, NHS ENGLAND, THE SECRETARY OF STATE FOR HEALTH AND THE GMC

1) The Secretary of State for Health should publish Directions making the NICE TB Guidance legally binding on NHSE, PHE and CCGs in order that treatment is provided to all patients until their infection is fully treated.

2) Health Protection Regulations should require that those with TB who are most at risk have full access to antibiotics and social support throughout the entire period of their treatment – including those who are at risk of deportation (see appendix three for HAPIA's proposed draft regulations).

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

4) Public Health England (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.

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

6) The General Medical Council should provide public assurances that doctors who breach the confidentiality of patients who are 'irregular migrants' will be subject to disciplinary procedures.

MATERNITY AND OBSTETRICS

The period 2015-16 has been a very challenging one for English maternity services, and one which is beginning to see new foundations laid for significant changes in how services are planned, commissioned and delivered. Alongside this are the changes to midwives' ways of working and legislative amendments affecting this specialised group of healthcare professionals. Nationally, and also through its representation on local groups, HAPIA continues actively to campaign for statutory services to engage and involve patients and the public effectively in the development of safer and user focussed services.

Revalidation for Nurses and Midwives

HAPIA Board member Elsie Gayle is a member of the NMC's Patient and Public Advisory Group, taking part in initiatives to improve how the regulator uses its policies and processes to protect the public: the Nursing and Midwifery Council (NMC) is the regulator for nurses and midwives in the UK, and it protects the public by setting the standards for the education, training, conduct and performance of nurses and midwives. As a result of concerns in the regulation of patient safety, the NMC was required to implement a new process by which each registrant would demonstrate their fitness to practise every three years. It replaces the PREP requirements which were deemed unsatisfactory. Following a period of consultation, planning and piloting, the new online Revalidation of nurses and midwives was scheduled to commence in April 2016.

(PREP - Post-registration education and practice is a set of Nursing and Midwifery Council standards and guidance designed to help midwives provide a high standard of practice and care.)

NMC public and patient engagement projects also engaged HAPIA in developing patient facing leaflets, and extending the reach of the NMC into unrepresented communities.

Maternity Service Issues monitored (2015 – 2016)

Morecambe Bay Inquiry

The Inquiry was set up by the Secretary of State for Health to examine the serious failures in care at The University Hospitals of Morecambe Bay NHS Trust, which resulted in death and harm to mothers and babies in the maternity services, over the period from 2004 to 2013. Reporting in 2015, the Inquiry found dysfunctionality in hospital, regulatory and supervisory mechanisms. The Inquiry made a number of recommendations for the adoption of significant service improvements, both locally and nationally. The persistence of the families involved demonstrated what can be achieved through effective patient and public engagement and involvement, when things do go wrong and families refuse to be silenced.

Reform of Midwifery Supervision

With the introduction of statutory supervision of midwives in the UK, midwives became the most highly regulated profession. On examining a number of maternity services reviews where mothers and babies had died or come to harm through poor care, certain gaps were revealed in the statutory supervisory processes. It was also found that there were significant conflicts between the NMC as regulator and the statutory supervisory mechanism. An inquiry by the Kings Fund recommended legislative changes to remove statutory supervision and bring all aspects of regulation under the umbrella of the NMC. This work has continued to be monitored as the NMC develops robust replacement structures in consultation with stakeholders.

NMC Project on "Understanding the progress and outcomes of black and minority ethnic nurses and midwives in relation to Fitness to Practice, for the Nursing and Midwifery Council (NMC)"

Over the years significant concerns have been raised about the disparities in treatment of and outcomes for black and minority ethnic NHS staff, and the consequential impact on the safety of patients. A number of separate reviews have been conducted by the NHS Workforce Race Equality Team, the Royal College of Nursing and the Royal College of Midwives in order to examine the situation for BME registrants in health professions. Similar concerns raised with the NMC led to the setting up of an advisory group, to support the conduct of a research project to examine these issues. HAPIA has continued to monitor the progress and development of the final report of this project which was scheduled to be completed in May 2016.

The National Maternity Review – Better Births. A Five Year forward plan for maternity care has reported, and HAPIA made a submission to the Health Committee's inquiry.

HAPIA WEBSITES

HAPIA operates several websites. The main HAPIA website is updated daily and provides information about Healthwatch and other major developments in the NHS and social care provision. See: **WWW.HAPIA2013.ORG**

The other websites are as follows:

www.healthwatchdevelopment.net - **HEALTHWATCH DEVELOPMENT**
Details HAPIA's research into the development of LHW and monitoring the transition from LINks to Healthwatch. The site presents data from Freedom of Information requests (Freedom of Information Act 2000) sent to 152 Local Authorities in England in 2013 and 2014.

http://www.rule43inquests.com – **PREVENTING FUTURE DEATHS**
Details of research into instances of Coroner's recommendations following a death.

http://www.revalidatingdoctors.net – **REVALIDATING DOCTORS**
Contains information about revalidation of doctors and leaflets for patients.

http://www.achcew.org - **ACHCEW ARCHIVE**
An archive site celebrating the work of the Community Health Councils, and the public involvement between 1974 and 2003.

WEBSTATS 2015

Site /Month	HAPIA	ACHCEW	RULE 43	HW DEV	REVALIDATION
AVERAGE MONTHLY HITS FOR HAPIA WEBSITES	4504	6631	2490	14493	4435

HAPIA PUBLICATIONS – 2014-15

THE BATTLE AGAINST TUBERCULOSIS in the UK Malcolm Alexander	Tuberculosis (TB) has become endemic in many parts of the UK. This report investigates which communities are infected, why treatment sometimes fails and whether the law on infectious diseases' detention helps or hinders. Stigma, poverty, migration, homelessness and the interface with illegality are explored in this report, as well as the impact of antibiotic resistance on TB treatment.
HEALTH AND SOCIAL CARE IN DETENTION **2015** Malcolm Alexander	Response to the CQC Consultation: "Our approach to regulating health and social care in prisons and young offender institutions, and health care in immigration removal centres"
THE UNIQUE FEATURES OF RURAL HEALTHWATCH 2014 Mary Ledgard	Approaches to delivering a local Healthwatch in a rural area
HAPIA CONFERENCE REPORT 2014 Catherine Gleeson and Mary Ledgard	Summary of Speakers' Presentations. Conference Speakers' Biographies.
PATIENT TRANSPORT SERVICES (PTS) HAPIA's recommendation for changes to PTS contracts 2014 Malcolm Alexander	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.
QUALITY ACCOUNTS AND THE SCRUTINY ROLE OF LOCAL HEALTHWATCH 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.

HEALTHWATCH AND IMMIGRATION REMOVAL CENTRES Healthcare for Asylum Seekers in Detention Centres August 2014	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 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".
COMPLAINTS AGAINST DOCTORS. **SHARING INFORMATION WITH PATIENTS AND CARERS** **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.
HAPIA'S GUIDE TO CASUALTY WATCH 2014	Guidance Notes for Casualty Watch Examples of Data Collection 30 & 60 Minutes Handover Breaches
REVALIDATION OF DOCTORS 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

REVALIDATION OF DOCTORS Working with Your Doctor to Improve Medical Care – A Guide for Patients	August 2014
See also: http://www.revalidatingdoctors.net	

MEMBERS AND AFFILIATES

During the year ended 31 December 2015, 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 of other organisations that support the objectives of HAPIA.
- Individuals active in developing more effective health and social care services 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.

This Report was approved by the Trustees on August _______ 2016 and is signed on their behalf by:

________________________	________________________
Malcolm Alexander **Director/Chair**	**John Larkin** **Director/Company Secretary**

INCOME AND EXPENDITURE ACCOUNT
FOR THE YEAR ENDED 31 DECEMBER 2015

	2015 Unrestricted Funds	2015 Total	2014 Total
	£	£	£
Incoming Resources			
Donations	-	-	2000
Membership and Conference Fees	1121	1121	3496
Payment for use of HAPIA resources	-	-	-
Total Incoming Resources	1121	1121	5496

Resources Expended			
Hire of Conference Halls and Events Management	779	779	5736
Steering Group Expenses (including hire of rooms)	199	199	740
Stationery, websites and other administrative expenses (including data analysis)	131	131	1340
Total resources expended	1109	1109	7816

Net Income (expenditure) for the year	12	12	(2320)
Total funds brought forward	394	394	2714

Total funds carried forward	406	406	394

BALANCE SHEET
31 December 2015

CURRENT ASSETS	**2015** **£**	**2014** **£**
Cash in hand	-	-
Cash at bank	835	1563
Debtors - (outstanding payments for annual conference)	350	304
CREDITORS		
Amount falling due within one year	779	1473
Total assets less current liabilities	406	394
Total net assets	406	394
RESERVES		
Unrestricted funds	406	394
Total Charity Reserves	406	394

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 2015 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. The Directors acknowledge 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 Statement were approved by the Trustees on ___________________2016 and signed on their behalf by:

_____________________ _____________________

Malcolm Alexander John Larkin
Director/Chair Director/Company Secretary

GLOSSARY

CCG … …	Clinical Commissioning Group
CQC … …	Care Quality Commission
DH … …	Department of Health
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
NICE … …	National Institute for Health and Care Excellence
OSC … …	Overview and Scrutiny Committee
PPI … …	Patient and Public Involvement
QA … …	Quality Account

APPENDIX ONE – SUMMARY OF INFORMATION ABOUT HAPIA

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

HAPIA Contact Details:

HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION – NORTH
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

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

APPENDIX TWO – MORE ABOUT HAPIA

AIMS AND OBJECTIVES

(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

(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

(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

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

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

BUILDING RELATIONSHIPS WITH THE PUBLIC

- Holding the health, social care and public health systems to account in relation to their duties to involve and to consult the public and to demonstrate positive outcomes.

- Monitoring the effectiveness of HWE and LHW in relation to their statutory duties and accountability to the public.

- Acting as a source of information and advice regarding safety, quality and effectiveness of health, social care and public health services.

- Advising lay and community organisations on the levers of influence in health, social care and public health services.

FUNDING

- Subscriptions from individuals, LHWs and other organisations

- Review of applications for funding to the DH, Department of Communities and Local Government (DCLG), HWE and grant giving bodies

- Review of funds to be raised from payments for commissioned research and survey work

- Income via an independent fundraiser working on a commission basis.

APPENDIX THREE – HAPIA’S DRAFT TB REGULATIONS

THE HEALTH PROTECTION (CONTINUITY OF CARE) REGULATIONS

DRAFT STATUTORY INSTRUMENT

2015 No. 000

PUBLIC HEALTH ENGLAND

The Health Protection (Continuity of Care) Regulations 2015

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 2015 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, that 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 paragraphs 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 45B (1)(c) of the Act these regulations allow the practitioner to advise :

a) the clinical commissioning group for the area where the 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 the
d) 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 45B(2)(b) of the Act, these regulations enable the practitioner to advise all or any of the bodies in 4.- a) - d) 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