



# 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**

**For the year ended 31 December 2023**

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**HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION**

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

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**Special Thanks to our Excellent Team**

- Ruth Marsden for her great Bulletins
- John Larkin – Company Secretary
- Polly Healy for her excellent support with our research projects, reports, publicity and websites

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## HAPIA STEERING GROUP MEMBERS 2023 and their PORTFOLIOS

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RUTH MARSDEN (until 15 July 2024) Yorkshire and Humberside <b>Trustee, Vice Chair</b>	Information and Communications Lead
ANITA HIGHAM South East	Integrated Care for Older Adults, Care of Young People with MH Problems
ELLI PANG South West	General Practice
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	Communications
MARY LEDGARD East of England	Theory and Practice of PPI
MALCOLM ALEXANDER London, <b>Trustee, Chair</b>	Patient Safety, Mental Health, Urgent and Emergency Care

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**WWW.HAPIA2013.org**

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## REPORT AND FINANCIAL STATEMENT FOR THE YEAR ENDED 31st DECEMBER 2023

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The Trustees have pleasure in presenting their Report and Financial Statement for the year ended 31 December 2023.

### **DIRECTORS AND TRUSTEES**

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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 (resigned 15 July 2024)**

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

### **OBJECTS OF THE HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION**

The Healthwatch and Public Involvement Association (HAPIA) is a not-for-profit company with exclusively charitable objects. The Company is committed to acting for 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

### 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. Promote community involvement in public consultations designed to influence key decisions about health and social services and hold service providers, commissioners, NHS England, Integrated Care Systems (ICS) and the Department of Health to account.
5. Promote open and transparent communication between communities across the country and their health services.
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

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, campaigning, 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

The main HAPIA website is updated regularly and provides information about Healthwatch and other major developments in the NHS and social care provision. The 2023 websites were as follows:

- **[www.hapia2013.org](http://www.hapia2013.org)** - The main HAPIA website.
- **<http://www.achcew.org>** - Archive site celebrating the work of Community Health Councils and public involvement between 1974 & 2003.

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**HAPIA CONFERENCES: Reports and Presentations can be seen at:**  
**[www.hapia2013.org/2015---agm.html](http://www.hapia2013.org/2015---agm.html)**

## HAPIA ACTIVITIES IN 2023

### HAPIA NORTH – RUTH MARSDEN

**Our Communications** hub has been maintained. It is noticeable, however, that information has become harder to source and when found, tends to be more 'opaque'. This is attributable to: commercial involvement; confidentiality; sub-contracting; overseas ownership; arm's length arrangements, and exemption from the duty to respond to FOIs', with which we are sadly becoming more familiar. An example is a Patient Transport Service using social enterprises/voluntary organisations, which caused concern by demanding a DNR notice before patients would be allowed on board the bus/taxi to get to their appointments. This demand naturally caused frissons of alarm.

Notwithstanding these issues, I am grateful to all colleagues and contacts who have done their best to assist with the provision of information that properly belongs in the public domain.

Work with **Mental Health** services has remained rather superficial, but has included much rewriting of literature, some inspection of premises, and a deep dive into the arrangements within prisons. The high incidence of mental health problems amongst prisoners is not new, but the waits for places in secure services/forensic psychiatry is disturbing. Always the Cinderella service, mental health provision often struggles to recruit, retain and maintain services for patients whose conditions are beyond a quick-fix.

**Pharmacy Provision**, or the lack of it, has proved a real challenge, as responsibility for it lies between Local Authorities and Integrated Care Boards. The complete withdrawal of Lloyds Pharmacy from the High Street market and down-sizing of the Boots 'empire', plus the closure of many independent pharmacies unable to cope with higher energy costs and increases in the minimum living wage, left something of a pharmacy-desert in some parts of the country. In one such case in the North, we saw huge queues outside the remaining chemists even before they opened in the morning, and long waits of up to two hours to get to the counter. The final straw was the inability of some elderly people to cope as exemplified when several collapsed in the street.



The abiding shame of this situation was taken by HAPIA North straight to the ICB, which then responded by allocating staff to visit the locality. HAPIA North set up a series of meetings attended by the ICB, LA, local Councillors and Local Healthwatch and mapped the evidence of under-provision. A detailed survey about pharmacy services drew hundreds of responses, all using adjectives such as 'shocking', 'terrible' and 'indefensible'. A Supplementary Statement, attesting to the gap in pharmacy-needs, due to reliance on the outdated 'Pharmacy Needs' Assessment', was drawn up and submitted to the Health and Wellbeing Board. The HWBB approved the statement and new pharmacy services' providers are currently going through the approval process. Diana Johnson, MP, from the neighbouring constituency, was kept in the loop to support her work in bringing to Parliament awareness of the increasing shortage of community pharmacies. Physical access to premises also posed difficulties for users of wheelchairs, mobility scooters and walking frames. Attempts to get action on this with the surviving Boots in the area, necessitated contacting the CEO of Boots, his Properties Team, their architect and development group. The Properties Team attended the store, noted the issues, and as a result stripped out the island-counters of toiletries etc. that impeded access. Through coordinating efforts with a local Councillor, it proved possible to get more chairs installed so the frail elderly could at least sit to wait.

**Local Authorities** are responsible for health-giving open spaces - parks, bridle ways, footpaths and the like. For three years, HAPIA North, representing small holders, disabled persons, and users of mobility vehicles, has worked with two LAs. Routes meant to be maintained as open and accessible are falling prey to neglect, encroachment, blocking by gas-pipeline development and off-shore wind farm connections to the National Grid. Further routes are eroded by illicit vehicle trespass. Liaison with police forces, with landowners, with Police and Crime Commissioners and with archaeology departments of Local Authorities is ongoing to tackle these problems. Keeping open routes for exercise and outdoor activity is important to the health and wellbeing of communities. HAPIA North has been invited to serve for a further three years on the Local Authority committee to help resolve these problems.

Some work started with **Carers**, and the strains they face amid ageing populations and ever reducing LA budgets. It is noticeable that the regular movement of staff, at all levels of service provision, both dislocates standards and dents confidence. Safeguarding Boards for Adults came under scrutiny as there seems to be opaque tracking of reported concerns. It was expected that a report of a concern would yield a case number/incident number/report number – something by which the issue could be followed up if the reporter continued to have concerns and looked for reassurance that steps were being taken. There is no such number or similar form of identity for safeguarding issues.

Further issues arose with the small but valuable grants available to carers groups. It is impossible now for small groups to open a bank account other than a 'business account'. This is beyond their capacity. The requisite audit-trail from the LAs cannot endorse the depositing of grants into personal accounts so sadly much of the available money lies fallow, inaccessible and unused. Large charities may hold the key – being able to facilitate the management of such funds.

**Patient Participation Groups** remain mandatory in the GP contract. Some local PPGs are very active and some are populated by HAPIA members. It was discovered that the provision of appliances - for urostomy, tracheostomy, stoma and bowel irrigation patients – lies outside the standard contract for pharmacies. Pharmacies can elect to provide these on prescription but do not have to do so. Appliance-items are often bulky and delicate, always expensive to the NHS system, and absolutely essential to those patients reliant on them. The appliances do not fit into the 'post-my-meds' boxes, designed to pass through a letter box. The non-arrival/lack of availability of these items can destroy independent living and makes it impossible for patients to leave the house, often even going to the bathroom. A determined and relentless campaign was undertaken to raise awareness of this issue, as it was discovered that even practice pharmacists were unaware of some of the problems experienced.

The other main arm of our PPG work has been refining the role of the receptionists/care navigators and upgrading their training and skills. The culture adopted by most practices has been challenged. Why should patients be greeted with notices saying 'we do not accept any abuse of our staff' and be obliged to "make a case" for why they have come for help at their surgery? How would staff feel if patients arrived wearing a sandwich board saying 'we will not be fobbed off, cross-questioned, and embarrassed when we seek medical care'?

**Research**, predominantly in primary care, remains part of the work of HAPIA North. Regular input into new information sources is undertaken, as well as, liaison with the research staff, and the provision of information about initiatives and opportunities for involvement in research. The take-up has been good – many local patients, conspicuously the retired and elderly, have become involved and are making a significant contribution to the model of future treatment and care in spheres such as dementia and loneliness.

Involvement has been maintained in **specialized commissioning**, mainly radiology-based. Consultations offer opportunities for feedback on patient-preference and experiences. Similarly, any opportunities for **Patient and Public Voice** roles are notified and circulated.

## **HAPIA SOUTH – MALCOLM ALEXANDER**

### **LONG COVID EXPLORING UNMET NEED**

#### **Report on our Meeting with Amina Ed-Deen Long Covid Engagement Lead, City & Hackney COVID Rehabilitation Service (CoRe)**

As the Covid Rehabilitation Engagement Lead, my role involves creating a partnership with voluntary sector organisations, the Local Authority and other stakeholders within the community, in order to increase awareness of Long Covid and to increase the support available for patients suffering from Long Covid.

The definition of Long Covid includes symptoms that could develop within the initial infection stage, then continue beyond a 12-week period. There are over 200 documented symptoms, the most common being fatigue, breathlessness, fast heart rate, palpitations, chest pain, brain-fog, lack of concentration and muscle aches and pains. The Office of National Statistics data reports that 2.1 million people in the UK have self-reported Long Covid symptoms – just over 3% of the population – as of 01 October 2022 (ONS 2022).

We have observed within City & Hackney the impact of health inequalities regarding access to CoRe services and this is now seen to be a Pan-London concern. Services provided to patients by CoRe include:

- Occupational Therapy
- Cognitive Behavioural Therapy (integrated with IAPT LTC)
- Psychological Wellbeing Practitioners (integrated with IAPT LTC)
- Physiotherapists- both musculoskeletal support and respiratory therapy
- Administration – booking, counselling, appointments and referrals
- General Practitioner – on a part-time basis
- Respiratory Consultant
- Access to Secondary Care specialties, e.g. Cardiology, Gastroenterology, Neurology and Rheumatology
- A&E direct referral
- Access to neighbourhood voluntary sector support services

### **Long Covid Service Pathway:**

When a patient/resident reports having symptoms believed to be Long Covid, or other unexplained symptoms, the first point of contact with the NHS is through their GP. There is currently no other method of self-referral, although this is now being worked on, in order to make the referral process smoother and easier.

The GP will carry out a range of tests to exclude the possibility of other causation. This will determine how the patient is referred forward. If referred to CoRe, the patient is offered an 'introductory session' and shown what support can be given – and is then offered the opportunity to 'opt in' or 'opt out' of the service. If the patient has 'opted-in' then he/she has a multi-disciplinary team assessment. This is a two-part assessment, either face-to-face or 'virtually', depending upon the patient's preference. However, CoRe do prioritise seeing patients face-to-face as this proves to be more effective and allows them to talk more freely about the issues of concern.

At the end of the assessment, a 'tailored plan' is developed according to the symptoms that they have presented with, and the things that they are struggling with the most. This will ascertain whether the patient should be referred to an individual Therapist/Practitioner, or whether group-based therapy would be best. The patient can then decide what feels best for them.

### **The Service Background**

There is a large disparity in the patient demographics in CoRe. Currently approximately:

- 73% have a white ethnicity
- 14% black and ethnic minority groups
- 8% mixed/other

Work is now being undertaken with local stakeholders to try to explain this demographic. The City & Hackney population data is largely 62% white British, and 38% black and minority ethnic groups. This work will also try to find ways to bridge the gap in order to improve the access and referral process to CoRe services. It is possible that there may not be enough awareness of the Long Covid service and what it can provide to patients.

### **Long Covid Inequalities in City & Hackney**

There is a significant lack of inequalities data in relation to Long Covid in City & Hackney. We know that Long Covid has impacted black and Asian minority ethnic groups more severely than other ethnicities. However, we are not seeing that in terms of who is accessing our services, which we know is not representative of the local population. We want to try and change that. We want to better understand how we can improve access and reduce any barriers facing the availability of our services.

## **Barriers to Service e-Survey**

The rationale behind this e-Survey is to understand the barriers faced by residents of City and Hackney, when seeking help or treatment for Long Covid, and how to identify areas of unmet need, in order to plan better health services for residents. The e-Survey is 'live' to any resident with confirmed or suspected Long Covid. The survey takes 10 minutes to complete. Residents can call, or email, the **CoRe** service if support is wanted to complete the survey. **CoRe** will return calls, and with the patient's consent, the team member can complete the form on the caller's behalf. Participants can also opt to enter a prize draw for a chance to win a 'store voucher'.

We had planned to undertake some interviews with people who have experienced Long Covid, in order to try and understand what the barriers were to accessing health services. Many people have come forward to take part in the survey, because this is obviously a really important issue for many people. At the last count we had 210 people with Long Covid symptoms who had filled in the survey, with 90 expressing an interest in being involved in further discussions, interviews or focus groups.

We also plan to hold two large events in which participants will be divided into smaller discussion groups. This will allow us to understand more about people's experiences of Long Covid and allow us to dig deeper. We shall explore all the barriers to accessing our service. Some people are not even getting as far as seeing the GP to discuss long-Covid symptoms. The e-Survey has been 'live' since just before Christmas 2022. **The following data is from the e-Survey, so far:**

<b>Procedures Taken</b>	<b>Percentage</b>
Tested 'positive' for Covid – 19	82%
Did not test 'positive' for Covid 19	17%
Received medical advice/treatment from their GP	50%
Received advice from Pharmacy services	15%
Received medical advice from NHS 111	26%
Did not seek medical support	13%
Number of patients admitted to Hospital	43%

**Long Covid** - Of the 62% (124 people) reporting that they had been diagnosed with Long Covid, their experiences were as follows:

<b>Symptoms Experienced</b>	<b>Patients</b>
Diagnosed with Long Covid	124
Fatigue	114
Difficulty in concentrating	113
Problems with memory	83
Shortness of breath	82
Muscle aches	94
Heart palpitations	47
Body pain	74
Other symptoms	46

## **Impacts on daily life for those suffering from Long Covid:**

<b>Impact on Daily Life</b>	<b>No of People</b>
Difficulty in caring for their family	63
Unable to work	79
Having to ask employer to adjust work role	78
Unable to attend education	25
Having to take a break from work/education	75
Difficulty in socialising with friends/family	85
Other	33

**We heard of other ways that Long Covid is impacting on people's lives:**

- Cannot live a 'normal' life
- Being completely bed-bound
- Lack of motivation – to exercise, maintain house/tidiness/hygiene, etc.
- Inability to pay rent as unable to work
- Effects on social life
- Feeling debilitated
- Lack of understanding from family/friends/colleagues
- Experiences of ignorance and discrimination

**Language barriers**

Responders were also asked if they thought that 'language' might have made it more difficult for them to find and use services for help, whilst experiencing Long Covid:

<b>Language Difficult</b>	<b>No. of People</b>
<b>Yes</b>	<b>61</b>
<b>No</b>	<b>95</b>
<b>Maybe</b>	<b>36</b>
<b>Not sure</b>	<b>11</b>

Of the 61 people stating that language was a barrier, many had English as a second language. Others, with English as their first language, reported 'brain-fog' causing them to struggle to express themselves, therefore, in a way, language and communication were a definite barrier. One respondent reported having Autism as a barrier. Within the question about language, we have noted that there are two parts ... the language that one speaks and the language one speaks when feeling unwell.

## **Disability or Long-Term Conditions**

We asked responders if they were living with disability or long-term conditions and if this could be affecting their ability to come forward and engage with services. Of the responders, 74 told us that they were living with a disability and/or a long-term condition. Some of the disabilities identified were:

- Breathlessness
- Difficulty in using public transport
- Unable to leave the house
- Unable to climb stairs
- Unable to stand or walk for long or far
- Impact on life activities
- Fear and anxiety

**Below are some of the reasons we were told why support for Long Covid symptoms has not been sought.**

<b>Reason</b>	<b>No of patients</b>
Using public transport/travelling	28
Finances and expenses	79
Caring Responsibilities	77
Employment	50
Language	17
Unaware of how to ask for help	46
Don't think there is anything that will help	46
Have tried to find help but was unsuccessful	49
Knew someone that tried to find help and had a bad experience	29
Other	11

These issues will be explored in more detail at planned events - including the possibility of offering free transport for people to come and engage with the **CoRe** service. Some worrying trends have been highlighted, which we shall look into.

## **Demographics**

We spoke with about half of the people from BME communities, and half of those from the white British communities.

- Most of the responders were between the ages of 21-60 years
- More women than men were coming forward to talk to us
- Half of the responders were in employment and the other half were unemployed

We appreciate the contribution made by everyone with Long Covid who has taken part in the e-Survey. This is an on-going piece of work and the next step – once we have completed gathering the data – will be to analyse the result in terms of whether there is a particular group of people reporting a particular barrier to accessing services – or whether there is a particular group of people who find it easier to access support.

## **AMINA ED-DEEN'S - Long Covid Engagement Lead** **ANSWERS TO QUESTIONS**

### **QUESTION from Chelliah Lohendran – Merton Healthwatch**

You mention that many white British people have sought your services, but that the BME groups are the most effected by Long Covid. What is stopping the BME groups with Long Covid accessing your services? If we contact the Primary Care Networks (PCNs), they should be able to provide some data.

**Answer:** We know that Covid-19 disproportionately affects BME groups and so if we go by that logic and that statistic, there surely must be a huge and considerable number of the BME population having Long Covid who are not accessing our services. We want to know why. It is proving quite hard to get this survey 'out there' and to share their experiences of barriers to accessing care. Perhaps, when visiting the GP, they were not listened to! This could be the reason we are not seeing a significant number from BME populations coming to our services. We are working with local community groups to contact residents directly and to get this survey circulated. One would think that GP Practices and PCNs should be able to get more data for us. It seems that some BME groups are not seeking care and are, therefore, missing from the data.

### **QUESTION from Stephen Sartain – Public Governor, Homerton Healthcare**

Long Covid is becoming a specialist area. There are many different symptoms of Long Covid and therefore different ways to identify it. Is there specialist training for Care Workers, doctors and other people in the hospital environment?

As a GP is the first 'port-of-call', are they having problems making referrals to the CoRe service? If a patient from a BME background visits the GP, are they less likely to be referred on to the CoRe service?

Is Long Covid considered to be a 'disability'? If people lose their jobs because of Long Covid are they entitled to benefits? This is an important issue.

**Answer:** Long Covid can be a very individualised experience. We see the most common symptoms are those of fatigue, breathlessness, chest pain, muscle aches and pain. They impact each person on a very individual basis. Some people are experiencing some severe symptoms, whilst others are coping a little bit better. In every case, these symptoms impact on their lives or their daily functions, so there is not actually any standardised or any sort of formal training as such. However, we do recognise that this is an issue. The impact on carers of people suffering with Long Covid, and family members or friends, is profound.

My role is to try to identify the support we can provide, even if it is just information or signposting. As an Engagement Lead, one of things that I am working on with other stakeholders, is to offer workshops – which could be to provide information and training on whatever the patient or their families feel is most important. This ties in with welfare and financial support. The development of services has been very slow, and I only came into this role in May 2022, so we are trying to do what we can with



the funding from the Government - and the uncertainty of how much longer the service will be available. We are waiting to find out if we have funding for a further year and we are unsure what support we can offer as a specialist service. We need to know that, in order to support families and patients in City & Hackney. I don't think my role exists in the other North East London Boroughs. I don't think that Tower Hamlets Long Covid Service has an Engagement Lead to focus on these issues. Nor does Barking and Havering, although they are working on it to get funding. In terms of training, when patients are referred to us, we identify their needs and how their symptoms are affecting them. We then do our best to support their needs, but in the terms of a general training programme, there is not anything yet, sadly!

As far as the referral process via the GP is concerned, we are working closely with the GPs, whilst understanding that they are under immense pressures. We have provided a training programme for GPs and Practice Nurses on the whole referral process, and the software programs that are used. Much of this is done on line, so we have made sure that the training is clear and that there are not any problems with the referral process.

We also hold 'webinars' for GPs and staff to keep them updated on the Long Covid progress reports and anything that they need to know when patients approach them in terms of Long Covid being recognised as a disability. Is Long Covid considered to be a disability? Unfortunately, we do not have any control over that. It is down to Government to decide. Initially, Long Covid was not recognised as a disability, so many people who could not work due to their symptoms and the impact on their lives, did not have a lot of support in terms of finances, or managing their finances. However, very slowly and gradually, it is changing.

We have a Care Co-ordinator in our Team and her role focusses upon supporting our patients to access other support in the community – e.g.: finding/looking for another job or making applications for PIP. We had one patient at risk of being evicted and the Care Co-ordinator provided support in this case too. It is a Government decision whether to classify Long Covid as a disability. We are highlighting just how Long Covid is impacting people and that some people are just unable to function normally.

#### **FEEDBACK from Nannette**

This is my own experience. I was once a Healthcare professional. I have passed 70 years of age. I was having a lot of chemotherapy and then came Covid-19. I didn't even know that I had Covid or Long Covid symptoms, but I was experiencing brain-fog. I began using my brain to do brain games and attending lots of meetings. Eventually, I saw a Neurologist who told me that I didn't have Dementia or Alzheimers, it was Long Covid. The GP told me that, owing to my age, I would have to "learn to live" with my brain-fog. This is now all about giving psychological support. It is frustrating to have to wait for an appointment and then come out empty-handed. It is better not to go anywhere rather than get this disappointment!

**Answer:** Firstly, a GP should not be telling patients that they should learn to live with anything because of their age! However, whilst there is no definite cure for Long Covid, there is ‘treatment’ and research is still on-going. There is more and more evidence coming out from research that some people are making a full recovery from Long Covid, whilst significant numbers are not making a full recovery. However, through rehabilitation, psychological support, respiratory support and occupational therapy, patients are learning to manage their symptoms.

As we see and treat more patients, we feel that nobody should have to “live with it”, especially on their own. They need support and we try to help as much as we can with techniques and treatments. It seems that 90% of people find it hard to cope. I would encourage anybody experiencing Long Covid symptoms to go to see their GP, ask for the diagnostic tests and ask to be referred to **CoRe**, if suitable. There is treatment available, and nobody needs to suffer on their own.

**QUESTION from Laurell Turner**

I work as an Occupational Therapist in Homerton. I have been there for years, and I am now about to move to a Long Covid Clinic in Central London Community Healthcare Trust. I am interested in hearing further information from your analysis of the data, about how you are trying to find out what’s going on, that is leading to the disparity you described from the survey and the engagement with stakeholders through community groups. I am also interested in hearing if you have any other insights from the data that you have gathered so far.

**Answer:** CVS organisations have good standing in the community, and they are the best organisations to work with and to raise awareness about the service we offer, about Long Covid and to dispel any myths. They also can signpost local residents to available services. We are also working to organise and establish a Peer Support Network, as a lot of our patients who have been accessing our services and have been discharged, say there is ‘no longer anything out there’ for them. They find that there is a lack of understanding about Long Covid and what is likely to happen in the longer term. This is still an emerging condition and many patients are feeling very isolated. Speaking to other people with similar conditions has proven extremely beneficial for patients with Long Covid. We are learning and working with other areas around the country about what they’ve set up, so we can establish more for City & Hackney patients.

**QUESTION from Alan Alexander – Chair, Cumbrian PPG**

I am Chair of a PPG in the far North of England and have three quick questions:

- You mention that your team is dedicated to Long Covid, or is it just a matter of accessing those specialists, specifically dedicated to Long Covid?
- Are your meetings with patients face-to-face, on line, or by telephone?
- Concerning the low access figures by some ethnic groups, have you looked at the age distribution – comparing white British with other British ethnicities?

**Answer:** We are dedicated to Long Covid, but because of the uncertainty of funding for the next year, continuing to run our services really depends upon the Government's priorities. Whether we merge with services providing similar conditions like Chronic Fatigue Syndrome, and other long-term conditions, remains to be seen. For now, we are a stand-alone, dedicated service working with patients with Long Covid. We run a variety of services for patients with Long Covid, but we prioritise meeting patients face-to-face. Sometimes patients opt for virtual meetings. Across all the different ethnic backgrounds, those accessing our services tend to be in the mid-20s up to 50s. We are seeing only a fraction of people over 50 or above 60.

**QUESTION from Councillor Mike Roberts, Rushmoor Borough Council**

Many political colleagues of mine (I am a Councillor) who have had Covid and who work in the NHS, have now got Long Covid. The pressure is building, and it is going to take concerted action to provide adequate and appropriate care and support for those who have got Long Covid, particularly for those who are BME. This issue has been highlighted by the Independent Scientific Advisory Group for Emergencies (Independent SAGE).

The issue with regard to staffing is that some staff who have Long Covid are still working. There doesn't seem to be a standard level of support within the NHS, and when it comes to communities and their needs, it seems that some areas are better staffed than others when it comes to providing expert care for people with Long Covid.

A lot of the issues that I see in Local Government are related to the quality of data. If the data is not showing the profile that you expect, or where there are gaps, then the interpretation of that by others above can be very patchy! I think that this is all part of a deliberate 'web' that the Government is bringing forward to ensure that not everybody knows exactly what is going on in other areas. One of the things I think that we need to do, is to share information and data, because Long Covid is not going way.

**Answer:** Disparity of service provision and support, in terms of different areas, largely comes down to funding. It is fortunate that City & Hackney - and our Service Lead, Stephanie Poulton – had the foresight to set up this service in January 2021. If staff in the NHS experience Long Covid symptoms, they are generally managed through Occupational Health. They tend not to access our service. It is vital to share information and data because Long Covid is not going away. We shall be sharing some of our e-Survey's interim results and what the data is telling us. We are still trying to push out this Survey and to get as many responses as we can, as this data is so important in showing where the need is, and is also essential when asking for more funding.

We are very fortunate to have the funding to employ a Care Co-ordinator who can support some of our patients, for instance, on how to navigate the PIP system, how to apply for PIP and how to show evidence of symptoms that are still not classed as a disability and consequently where patients may not have received PIP.

#### **QUESTION from Stephen Sartain**

Because of the pressures GPs are under, there has been a big campaign recently requesting patients to ring the NHS 111 Helpline, or to go and visit a Pharmacist. Could this be a reason why people have not been going to their GP unless absolutely necessary? I have worked in welfare benefits for over 30 years, and I wondered if anybody had actually applied for Personal Independent Payments (PIP), then received payments or were rejected? I believe that Long Covid sufferers meet all the conditions required to receive these payments.

It is correct that Long Covid sufferers are scared of losing their jobs. Concerns are about what the employer will say/do when told that they must take time off work – and whether or not they will get sick-pay. It is likely that the person will lose their job, especially if they haven't worked there for long. It is frightening enough to lose one's job, let alone having to apply for benefits.

It might be helpful to put a Survey/Questionnaire in local newspapers, e.g. Hackney Today. This is issued by the Council and would be helpful in notifying the public that a survey is being carried out, as not everyone has access to a computer. Another useful newspaper could be the Hackney Gazette.

**Answer:** That's a great idea to put the survey in Hackney Today. We shall be keeping the survey going for a while. We know that GP access is a huge issue currently. There are bound to be patients who have tried to attend an appointment and struggled with not being seen straight away. Many might feel discouraged and have given up.

We are also running a survey for GPs, to ask them what their experiences of referring into the Long Covid services are like, whether they think that the process is working, and whether there is anything that we can do from a Long Covid point of view. We want to help people suffering from Long Covid to move smoothly through the system. Unfortunately, I do not know the answer to the PIP question. I shall take this back to the Team to see if we can add a question into the survey on this topic. Many people are definitely worried about losing their jobs, and when you think of Zero Hours Contracts, there will be many working 'cash-in-hand' and, therefore, unable to apply for Sick Pay. This will have serious and worrying effects.

### **Possible Causes of Long Covid - Jos Bell's Research**

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I have had Long Covid now for two years. I contracted it while Chairing a meeting in the House of Commons. I contracted Covid a second time and had some really bad weeks and months and experiences following this. I decided to link into international research, and had great support from my GP and my Long Covid Consultant at King's. There is now a lot of evidence coming from world-class research as to the actual clinical elements of Long Covid that go well beyond the personal experience of patients, e.g. that they do not feel well after Covid and do not seem to get better.

I am having to live a very different life to the one I had before Long Covid. My GP Practice has a website on which there is a section covering Long Covid, but the experience of many other patients is that their GP may just 'fob them off' because they do not understand the symptoms of Long Covid. The patient may be fatigued and struggling to describe their symptoms, so this won't necessarily result in a positive referral.

Internationally, there have been some brilliant research projects and I have linked in with some of them because I needed to understand better what was going on with me. I could not just sit/lie down and 'give up'. I now have lots of research papers from international sources, and have a good overview of the key elements of Long Covid. For instance, that it is a vascular disease and involves endothelial damage, which can go on to create more organ tissue injuries, affecting the autonomic nervous system; that is why some people feel so dizzy with Long Covid.

There is a treatment called Apheresis that patients have been able to access in Germany, Cyprus and South Africa. This is helping, but again, not everybody reacts positively to it, or needs the same level of treatment. Mitochondrial damage to the oxidative chain results in our oxygen take-up being reduced. The metabolic system is also impacted and some people are taking supplements to help and override the fact that there are nutritional issues.

The UK is in one of the worst situations, compared to parallel countries, in terms of finding biomarkers. Once we get a list of biomarkers that are clearly Covid diagnostic

tools, rather than using generic tools, which do not show where the damage is, patients can be treated more effectively.

(Biomarkers are a biological molecule found in blood, other body fluids, or tissues that are a sign of a normal or abnormal process, or of a condition or disease).

### **Recognising Long Covid as a Disability - Steven Sartain**

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Thanks to Amina Ed-Deen and Jos Bell I am now more persuaded – given my Welfare Benefit background - that there needs to be some clarity on what Long Covid actually is, in terms of being a medical disability. There is clearly a spectrum – some have a very mild form, and others a very extreme form. I will use Jos's information to put a very concrete case to say that this is a disability, and I think it would make things clearer and enable access to a lot of benefits and help, if it were clarified in this way.

## HAPIA PUBLICATIONS

<p><b>PUBLIC INVOLVEMENT IN THE NHS: LEGISLATION, REGULATIONS AND DUTIES 2017</b></p>	<p>The law on public involvement.</p>
<p><b>HEALTHWATCH CAMPAIGNING BRIEFING NOTE - 2017</b></p>	<p>A collation of evidence demonstrating the right of local Healthwatch to campaign for service improvements.</p>
<p><b>HAPIA CONFERENCE REPORT 2014</b> Cath Gleeson &amp; Mary Ledgard</p>	<p>Summary of Speakers' Presentations. Conference Speakers' Biographies.</p>
<p><b>PATIENT TRANSPORT SERVICES (PTS)</b> HAPIA's recommendation for changes to PTS contracts. October 2014</p>	<p>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.</p>
<p><b>QUALITY ACCOUNTS AND THE SCRUTINY ROLE OF LOCAL HEALTHWATCH</b> HAPIA Briefing Note Catherine Gleeson 27 October 2014</p>	<p>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.</p>
<p><b>HEALTHWATCH AND IMMIGRATION REMOVAL CENTRES</b> Healthcare for Asylum Seekers in Detention Centres August 2014</p>	<p>Numerous reports from Her Majesty's Inspector of Prisons (HMIP) indicate serious problems in the standards of healthcare provided.</p>

<p><b>HEALTHWATCH AND IMMIGRATION REMOVAL CENTRES - Continued</b></p>	<p>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”.</p>
<p><b>COMPLAINTS AGAINST DOCTORS. SHARING INFORMATION WITH PATIENTS AND CARERS</b> Improving Doctor’s performance</p>	<p>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.</p>
<p><b>REVALIDATION OF DOCTORS</b> The Role of Case Manager in Improving the Performance of Doctors Sharing Information with Patients, Carers and the Public</p>	<p>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.</p>

<p><b>LEAFLET</b></p>	
<p><b>REVALIDATION OF DOCTORS</b> Working with Your Doctor to Improve Medical Care – A Guide for Patients</p>	<p>August 2014</p>



## MEMBERS AND AFFILIATES

During the year ended 31 December 2023, membership remained active. 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  
and is signed on their behalf by:

2024

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Malcolm Alexander  
Director/Chair

John Larkin  
Director/Company Secretary

**INCOME AND EXPENDITURE ACCOUNT FOR THE  
YEAR ENDED 31 DECEMBER 2023**

	<b>Unrestricted Funds 2023</b>	<b>Total 2023</b>	<b>Total 2022</b>
<b>Incoming Resources.</b>	£	£	£
<b>Donations.</b>	-	-	-
<b>Membership fees.</b>	50	50	80
<b>Total Incoming Resources.</b>	50	50	80

**Resources Expended.**

Websites and Administrative Expenses.	-	-	88
Copyright fee for use of photograph.	-	-	180
Companies House fees expenses.	40	40	40
<b>Total Resources Expended.</b>	40	40	308
<b>Net Income(expenditure) for the year.</b>	10	10	(228)
<b>Total funds brought forward.</b>	1443	1443	1671
<b>Total funds carried forward.</b>	1453	1453	1443

## BALANCE SHEET      DECEMBER 31, 2023

	2023	2022
<b>Current Assets</b>	£	£
Cash in hand	-	-
Cash at bank	1453	1443
Debtors	-	-

<b>Creditors</b>		
Amounts falling due within one year	-	-
Total assets less current liabilities	1453	1443
<b>Total net assets</b>	<b>1453</b>	<b>1443</b>

<b>Reserves</b>		
Unrestricted funds	1453	1443
<b>Total Charity Reserves</b>	<b>1453</b>	<b>1443</b>

### 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 2023 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:

\_\_\_\_\_ 2024 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
BHA ...	...	Black Health Agency
CPD ...	...	Continuing Professional Development
CCG ...	...	Clinical Commissioning Group
CQC ...	...	Care Quality Commission
CRG ...	...	Clinical Reference Group
DH ...	...	Department of Health
DNR ...	...	Do Not Resuscitate
E&V ...	...	Enter and View
ELFT ...	...	East London Foundation Trust
EOC ...	...	Emergency Operations Centre
GMC ...	...	General Medical Council
HAPIA ...	...	Healthwatch and Public Involvement Association
HCPC ...	...	Health Care Professions Council
HMCIP...	...	Her Majesty's Chief Inspector of Prisons
HMIP ...	...	Her Majesty's Inspectorate of Prisons
HSJ ...	...	Health Service Journal
HWBB ...	...	Health and Wellbeing Board
HWE ...	...	Healthwatch England
IAPT ...	...	Improving Access to Psychological Therapies
IAS ...	...	Independent Advocacy Service
IC ...	...	Intelligent Conveyancing
ICAS ...	...	Independent Complaints Advocacy Service
ICB ...	...	Integrated Care Board
ICS ...	...	Integrated Care System
IRP ...	...	Independent Reconfiguration Panel
IMB ...	...	Immigration Monitoring Board
IRC ...	...	Immigration Removal Centre
LA ...	...	Local Authority
LAS ...	...	London Ambulance Service
LHW ...	...	Local Healthwatch
LTC ...	...	Long Term Conditions
MSLC ...	...	Maternity Services Liaison Committee
MHCC ...	...	Manchester Health and Care Commissioning
NAOPV ...	...	National Association of Prison Visitors
NHSE ...	...	NHS England
NHSI ...	...	NHS Improvement
NHSR ...	...	NHS Resolution
NICE ...	...	National Institute for Health and Care Excellence
NIHR ...	...	National Institute for Health and Care Research
NMC ...	...	Nursing and Midwifery Council
OPD ...	...	Outpatients Department

OPV	...	...	Official Prison Visitor
OSC	...	...	Overview and Scrutiny Committee
PHE	...	...	Public Health England
PoS	...	...	Place of Safety
PPG	...	...	Patient Participation Group
PPI	...	...	Patient and Public Involvement
PRF	...	...	Patient Report Form
PTS	...	...	Patient Transport Service
RAG	...	...	Red, Amber, Green
SALS...	...	...	Staff Advice and Liaison Service (WMAS)
STP	...	...	Strategic Transformation Plan
TB	...	...	Tuberculosis
URL	...	...	Uniform Resource Locator
WMAS...	...	...	West Midlands Ambulance Service
WTE	...	...	Whole time equivalents

## APPENDIX ONE – NHS CONSTITUTION - 20 PLEDGES

### Pledges

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This Constitution also contains pledges which the NHS is committed to achieve, supported by management and regulatory systems. The pledges are not legally binding because they express an ambition to improve, going above and beyond legal rights.

There are 20 Pledges which are as follows:

### The NHS pledges to:

- 1) Provide convenient, easy access to services within the waiting times set out in the Handbook to the NHS Constitution.
- 2) Make decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered.
- 3) Make the transition as smooth as possible when you are referred between services, and to put you, your family and carers at the centre of decisions that affect you or them.
- 4) Identify and share best practice in quality of care and treatments.
- 5) Provide screening programmes as recommended by the UK National Screening Committee.
- 6) Ensure those involved in your care and treatment have access to your health information so they can care for you safely and effectively.
- 7) Ensure if you are admitted to hospital, you will not have to share sleeping accommodation with patients of the opposite sex, except where appropriate, in line with details set out in the Handbook to the NHS Constitution.
- 8) Anonymise the information collected during the course of your treatment and use it to support research and improve care for others.

- 9) Ensure where identifiable information has to be used, to give you the chance to object wherever possible.
- 10) Inform you of research studies in which you may be eligible to participate.
- 11) Share with you any correspondence sent between clinicians about your care.
- 12) Inform you about the healthcare services available to you, locally and nationally.
- 13) Offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices. This will include information on the range and quality of clinical services where there is robust and accurate information available.
- 14) Provide you with the information and support you need to influence and scrutinise the planning and delivery of NHS services.
- 15) Work in partnership with you, your family, carers and representatives.
- 16) Involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one.
- 17) Encourage and welcome feedback on your health and care experiences and use this to improve services.
- 18) Ensure that you are treated with courtesy, and you receive appropriate support throughout the handling of a complaint; and that the fact that you have complained will not adversely affect your future treatment.
- 19) Ensure that when mistakes happen or if you are harmed while receiving health care you receive an appropriate explanation and apology, delivered with sensitivity and recognition of the trauma you have experienced, and know that lessons will be learned to help avoid a similar incident occurring again.
- 20) Ensure that the organisation learns lessons from complaints and claims and uses these to improve NHS services.

## APPENDIX TWO – SUMMARY OF INFORMATION ABOUT HAPIA

### Company Secretary:

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John Larkin – Fornham Lodge, 4 Verna Street, Marham Park, near Fornham All Saints, Bury St Edmunds, Suffolk, IP32 6FU.

Tel: 07493686549

Email: [larkinjq1946@gmail.com](mailto:larkinjq1946@gmail.com)

### HAPIA Contact Details:

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#### 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](mailto:ruth@myford.karoo.co.uk)

#### HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION - SOUTH

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30 Portland Rise, London, N4 2PP

Tel: 020 8809 6551 or 07817505193

Email: [HAPIA2013@aol.com](mailto:HAPIA2013@aol.com)

Website: [www.hapia2013.org](http://www.hapia2013.org)

### Trustees of the Charity:

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John Larkin	Malcolm Alexander
Elsie Gayle	Ruth Marsden (until 15/07/2024)

### Rotation of Directors

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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**

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Charity No: 1138181

Originally known as National Association of LINKs Members until the company name changed in December 2013 to Healthwatch and Public Involvement Association (HAPIA).

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

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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 the name of Healthwatch and Public Involvement Association.

## **Governing Documents:**

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Memorandum and Articles of Association as incorporated.

## **Charitable Objects:**

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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:**

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

## APPENDIX THREE – MORE ABOUT HAPIA

### 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, Patients' Forum Ambulance Services (London) Ltd and the Friends of the Halcyon Birthing Centre.

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.