

ACHA

Academic Centre for Healthy Ageing

Public and Patient Involvement and Engagement (PPIE) Strategy

Year Zero

ACHA's 'Year Zero' Patient and Public Involvement and Engagement strategy has been developed to support the active involvement of patients and the public in the design and mobilisation of our brand-new research centre.

This strategy recognises the invaluable contributions of patients and the public in ensuring meaningful patient and public involvement and engagement is at the heart of every stage of the establishment of ACHA.

Our aim is to ensure research and professional education programmes are co-produced in partnership 'with' or 'by' members of the public rather than pursuing approaches which are framed around activities 'to', 'about' or 'for' local people.



bartshealth.acha@nhs.net



acha.qmul.ac.uk



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1. Introduction

1.1 Introducing the Academic Centre for Healthy Ageing

- The Academic Centre for Healthy Ageing (ACHA), co-located at Whipps Cross Hospital, is anchored to the Barts Health NHS Trust ambition to transform Whipps Cross to become a world class centre of excellence, leveraging academic collaborations with Queen Mary University of London and other partners to achieve outstanding care and support patients within north east London to live healthier lives for longer.
- While the NHS has implemented policy and practice changes to improve care and support provision, there are gaps in research and knowledge that hinder the effectiveness of these changes. To help address these gaps, ACHA is taking a unique and innovative approach by placing research on the front line of local health and care services to create a 'living laboratory'.
- This approach will bring together frontline experience and 'real-world' situations with academic research to improve understanding of the specific needs of local populations and develop targeted interventions and services accordingly.
- All our research happens in real world 'frontline' care settings and involving patients and caregivers. Because of this, we can produce high quality evidence of what works. Connecting with national experts and networks, we can use this knowledge to change services to better support people as they grow older.

National Context:

- Chief Medical Officer for England, Chris Whitty's, report on healthy ageing emphasises the need to address health issues to improve the quality of life for older adults. The primary goal is to reduce the time spent living with ill health by delaying disease onset through primary prevention (by governments to reduce risk factors) and secondary prevention (by the NHS to slow disease progression).
- Inequality in ageing rates is largely preventable and influenced by social and economic environments. This is evident in the gap in biological age between those in poverty, facing multiple risk factors like smoking and limited green spaces, and those in less deprived areas. The rise in multimorbidity, where multiple chronic diseases interact, highlights the need for comprehensive care rather than treating each illness separately. The current healthcare system's single-disease approach can lead to fragmented care and reliance on multiple medications.
- Frailty, while related to multimorbidity, specifically identifies older individuals at high risk of adverse outcomes like disability and falls. Early identification can slow frailty progression and delay loss of independence. Improving infrastructure for transport, leisure, exercise, and housing is crucial, as is addressing mental health in later life with targeted interventions.
- Research often excludes older adults, yet they should be a primary focus, particularly in social care, frailty, and ageing in ethnic minority populations. Resources should be directed to areas of greatest need, with government addressing environmental factors to prevent early ageing. Promoting lifelong exercise, reducing smoking, and minimising air pollution are key strategies. Expanding screening programmes to underserved groups and enhancing data collection and research on older adults' health are essential for improving care and support for the ageing population.

1. Introduction (continued)

1.2 Our Vision for PPIE

- For ACHA to achieve its full potential, the views and needs of our diverse local communities must be at the heart of shaping what we do: our research, our education programmes, and, most importantly, how we will support and inform health and care service transformation.
- We are committed to building sustainable public engagement approaches by using all available channels and methods to build strong foundations in the community and to ensure that the research and innovation undertaken by ACHA remains focused on the priorities and health needs of the diverse demographic within the boroughs of Waltham Forest, Redbridge and West Essex.
- We believe that the key to making positive and sustainable changes to support healthy ageing, is to involve the public and patients in co-produced research and service improvement initiatives. Ongoing patient and public involvement will help to ensure that research and innovation undertaken by ACHA remains focused on the priorities and health needs of the diverse communities within the boroughs of Waltham Forest, Redbridge and West Essex. We are committed to recognising, documenting and celebrating peoples' contributions, providing feedback on the outcomes of involvement to demonstrate the value people are adding.
- ACHA intends to establish meaningful relationships with our patients, carers and community organisations and collaborate with multi-disciplinary partners and stakeholders to share best practice, reduce duplication and ensure that we are incorporating Patient and Public Involvement and Engagement (PPIE) expertise in the development and establishment of this brand-new research centre.



2. Scope

2.1 Purpose

- Our Patient and Public Involvement and Engagement (PPIE) strategy is designed to actively involve and engage patients and the public in the development and establishment of ACHA.
- The purpose of this document is to outline ACHA's principles, values and the intended approach to Patient and Public Involvement and Engagement to inform and guide the 2024/25 PPIE Plan, and to signal the centre's commitment to working in collaboration with our local communities.
- It is important to develop a broad and holistic approach to understanding the priorities and perspectives on healthy ageing. To understand the needs of the diverse communities within each borough, we must work in collaboration with patients and the public. To listen and learn from their experiences, in the hope of addressing the range of social, physical and mental health factors, including the health disparities and inequalities, that influence the wellbeing and quality of life of patients and local communities as they age.
- PPIE will also allow us to tailor research and initiatives to address the specific and unique needs within each locality, to create sustainable and realistic changes that are person and community-centred for better healthy ageing.

2.2 Our Population

- Whipps Cross Hospital serves a local population characterised by a high prevalence of multiple long term health conditions which generate complex health and care needs. These are evident through poor quality population ageing, with increased risk of developing clinical frailty and experiencing health outcome disparities which include reduced healthy life expectancy. The redevelopment of Whipps Cross Hospital is in alignment with NEL care system plans to transform services and build a sustainable workforce, equipped to address unmet care needs and outcome disparities. These are powerful drivers for care system-led change which underpin our proposal to develop ACHA.
- Understanding the demographic make-up of each borough will help us to strategically involve and engage members of the public and patients who are representative of our local communities. However, it is important to consider the limitations of the available data, as there may be variations between wards within each borough.

A: Waltham Forest

Waltham Forest stands out as one of the most diverse boroughs in England and Wales, ranking 18th in diversity. Nearly 47% of its residents come from non-white backgrounds. Within the White category, there has been a notable increase in those identifying as White-other, rising from 15% in 2011 to 17% in 2021 (ONS Census, 2021). The borough has a relatively young population, with a median age of 35.6 years. Only 10% of residents are aged 65 and over, which is lower compared to London (12%) and the UK (18%) as a whole (ONS, 2021).

2. Scope (continued)

Health-wise, about 6% (12,300) of Waltham Forest residents consider their health to be 'bad' or 'very bad'. Additionally, 13% report that their daily activities are limited due to health issues, compared to the national average of 17%. Among residents aged 65 and over, approximately 42% (10,906 individuals) have a long-term health condition or disability. In terms of sexuality, around 4.5% of the population over the age of 16 identify as LGBTQ+.

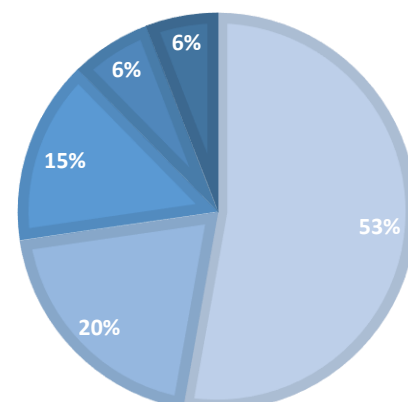
Waltham Forest Borough also faces significant socio-economic challenges. It is the 12th most deprived out of the 32 London boroughs, according to the Index of Multiple Deprivation (IMD, 2019). Employment rates, according to the ONS Annual Population Survey in Waltham Forest are slightly below the London average, with 71.3% of residents aged 16-64 in employment as of September 2023, compared to the London average of 74.6%. The unemployment rate, based on the proportion of 16-64-year-olds claiming unemployment benefits in December 2023, stands at 6.1%.

- **Ethnicity of adults 65 and over:** Within Walthamstow there was a higher percentage of older adults identifying as White and a slightly lower percentage of adults identifying as Asian, Mixed or Other, compared to the population of all adults in the borough (ONS Census, 2021).
- **Health of adults 65 and over:** Of older adults within the borough, 12% said they were in bad health, whilst 4% said that they were in very bad health. Nineteen percent said that they were disabled and limited 'a little' in their activities, whilst 20% said that they were disabled and 'limited a lot' (ONS Census, 2021), compared to 9% and 8% in the whole adult population, respectively.
- **Education of adults 65 and over:** Forty five percent of adults over 65 reported having no formal qualifications, significantly higher than the general population (18%).

Population by race in Waltham Forest (Source: ONS 2021 census)

- **White** - 147,024 people or 52.8%
- **Asian** - 55,545 people or 19.9%
- **Black** - 41,647 people or 15.0%
- **Mixed** - 17,983 people or 6.5%
- **Other** - 16,229 people or 5.8%

■ White ■ Asian ■ Black ■ Mixed ■ Other



2. Scope (continued)

B: Redbridge

Redbridge, a borough celebrated for its rich diversity and cultural vibrancy, ranks as the 4th most diverse borough in England. In 2021, nearly half of Redbridge's population (47.3%) identified as Asian, marking a 5.6% increase since 2011. Overall, 65.2% of residents belong to an ethnic group other than White, reflecting the dynamic and multicultural community that thrives here.

Redbridge's demographic profile reveals a average age of 36 years, slightly older than London's median of 35 years. Approximately 12.2% of the population is aged 65 or older, which aligns closely with the UK average of 12% but is lower than the national figure of 18%, according to the ONS (2021).

Health statistics in Redbridge show a mixed picture. While 5.2% of residents report their health as "bad" or "very bad," 14.6% experience some degree of limitation in daily activities due to long-term health conditions or disabilities, which is slightly better than the national average of 17%.

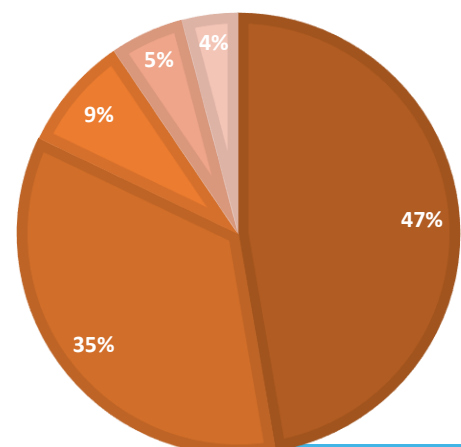
Economically, Redbridge faces challenges, being the 22nd most deprived borough among London's 32 boroughs, according to the Index of Multiple Deprivation (IMD, 2019). Despite this, the employment rate for those aged 16-64 was 70% in 2023, just below the London average of 74.6%. The unemployment benefit claimant rate for the same age group was 5% in December 2023, highlighting ongoing efforts to improve job opportunities for residents.

- **Age of Older Adults:** In Redbridge, the older population (65 years and above) makes up about 12.2% of the total population, which is approximately 37,932 individuals out of 310,260 as of the 2021 Census. This includes around 8,435 people aged 80-89 and 1,943 people aged 90 and above (Redbridge Council) (City Population).
- **Health of Adults 65 and Over:** Older residents in Redbridge face significant health challenges despite generally high life expectancy (84.1 years for women, 80.1 years for men). They experience high rates of long-term conditions such as diabetes and cardiovascular disease, and mental health concerns like dementia are prevalent. Socioeconomic disparities and stigma around mental health and other conditions can hinder access to health and social care services (Office for National Statistics (ONS) and the Redbridge Annual Public Health Report).

Population by race in Redbridge (Source: 2021 ONS census)

- **Asian** - 146,833 people or 47.3%
- **White** - 107,974 people or 34.8%
- **Black** - 26,096 people or 8.4%
- **Other** - 16,622 people or 5.4%
- **Mixed** - 12,736 people or 4.1%

■ White ■ Asian ■ Black ■ Other ■ Mixed



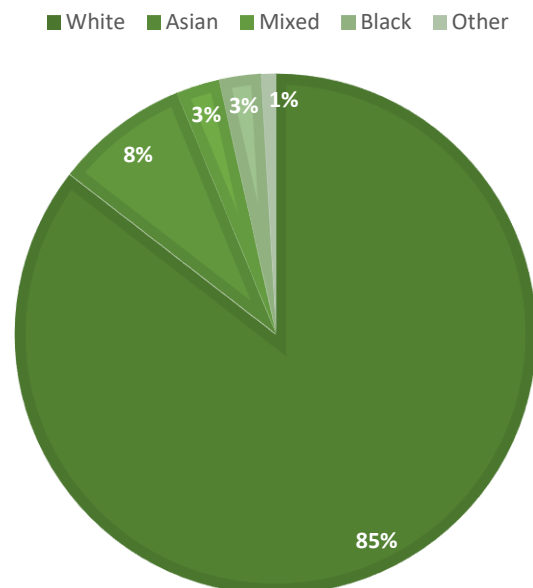
2. Scope (continued)

C: West Essex (Loughton, Buckhurst Hill and Chigwell PCN)

West Essex is home to a significant number of older adults, with 19.57% of our population being 65 or over as of September 2021. This brings a wealth of experience and depth to the local culture, however there are challenges as currently, 6% of our residents are unemployed. Most of the residents, 85.5%, identify as white, which is slightly higher than the 81.7% across England and Wales, reflecting a unique cultural composition.

- Population by race in Loughton, Buckhurst Hill and Chigwell PCN (Sources: 2015/16; Hertfordshire & West Essex ICS Primary Care Network Profile 2021: Loughton Buckhurst Hill & Chigwell PCN)

- **White** – 85.5%
- **Asian** – 8.3%
- **Mixed** – 2.7%
- **Black** – 2.6%
- **Other** – 0.9%



2. Scope (continued)

2.3 Our Local Network

As well as working alongside patients and the public, ACHA aims to establish meaningful partnerships with key local and national organisations to ensure that our work is aligned and can tap into existing knowledge, guidance and expertise, rooted in the lived experiences and priorities of the communities in Waltham Forest, Redbridge and West Essex.

Voluntary, Community and Social Enterprise (VCSE)	<p>Connecting with existing networks, resources and expertise will not only support our research efforts but help us to build trust and credibility within local communities. We aim to bridge the gap between research and impact by creating sustainable and mutually beneficial relationships with our local community organisations.</p> <p>Community stakeholders include: Healthwatch, AGE UK and MIND in Waltham Forest, Redbridge and West Essex. VCSE organisations, Citizens Advice Bureau, Carers First, Redbridge Rainbow Community, Legal Remedy Centre, African & Caribbean Association (ACA), African & Caribbean Community Health Network (ACCHN) and the Waltham Forest Community Hub.</p>
Local Authority	<p>We have partnered with Waltham Forest, Redbridge and West Essex local council representatives and strategists.</p> <p>These partnerships will enable us to discover ongoing work within each locality and share learning with community stakeholders/representatives working with diverse or marginalised communities.</p>
Queen Mary University of London	<p>We will work alongside professors, academics, lecturers, researchers and the Centre for Public Engagement to bring together diverse perspectives and resources.</p> <p>This will accelerate our research findings, promote solutions and to ensure that our health and care research has a lasting and positive impact on scientific understandings and patient care.</p>
Joint Research Management Office (JRMO)	<p>Collaborating with our JRMO partners will ensure compliance with regulatory requirements and assist us in maintaining an effective research environment.</p> <p>Our colleagues within the Engagement Team at the JRMO will connect ACHA to a well-established local engagement function and network of support.</p>
Health and Care professionals	<p>Our partnerships with health and care professionals will be crucial for bridging the gap between scientific findings and practical solutions in clinical settings.</p> <p>Their involvement ensures that research questions are relevant to clinical practice and ensures that findings can be integrated into patient care. We will build relationships with geriatricians, nurses, applied health care professionals, engagement colleagues, service leads and other health and care professionals across north east London.</p>
Patients and public	<p>Co-production with patients and the public is essential to health and care research. We will ensure we are incorporating diverse perspectives, preferences and priorities in the research process. We will involve patients, patient committees, steering groups, carers and local community representatives.</p>

3. Our PPIE Principles

1 Understand what matters to our communities

We understand the importance of listening to the voices of our diverse communities, to give lived experience a platform to improve care and to support people to age well.

2 Build trust with marginalised communities and those affected by health inequalities.

We will prioritise connecting to communities where they are and where they feel safe and engage in meaningful discussions with clear aims, actions and next steps.

3 Reflect the local diversity of thought and abilities

We will ensure we are as inclusive as possible in our practice, respecting the diverse abilities, values and cultures of our local population.

4 Work closely with our partners and network organisations, making use of existing knowledge

We will avoid duplication, combine local resources and respect the time and effort of our local partners.

5 Putting voices of the local community at the heart of everything we do and at every stage of our work

We intend to focus our research on the priorities of the local community via true and meaningful co-production, influencing decision-making directly with the voices of local communities.

6 Supporting and empowering patients, carers and local communities in involvement and engagement

We will offer training and resource, make contributions and convey recognition for the time and input our participants offer ACHA.

7 Being transparent by sharing feedback with communities and being accountable

Our activities will be approached with honesty and transparency, ensuring there is feedback and consistent communication.

4. Methodology and Activities

4.1 Engagement

- ACHA’s overall approach to engagement is three pronged; Partner, Engage and Inform. Our approach to engaging with the public and patients will be centred around the “Engage” methodology in year zero, whilst we work to establish the centre and begin our research activities.
- We are committed to using all available methods to build and sustain our public engagement approaches including recruitment of the public and patients through primary and secondary care services through advertising, town hall meetings, social media, newsletters, a public website and involvement in community activities.
- Further planned activities include:

Level of Involvement	Activities	Method
Collaborating	<u>Community Advisory Group (CAG)</u> <ul style="list-style-type: none"> • Inform, evaluate and implement ACHA’s PPIE Strategy • Inform other key policies and strategies in ACHA • Support to identify and access diverse communities • Support to raise awareness and offer education programmes training around the importance of, and ACHA’s approach to, Patient and Public Involvement and Engagement 	<ul style="list-style-type: none"> • Bi-monthly strategic meetings
Involving and Consulting	<u>Patient and Public Involvement</u> <ul style="list-style-type: none"> • Provide insight, expertise and experience at every stage of the research process. For example, identifying key priorities for research and service development, supporting the design and development of research protocols, supporting evaluation and implementation strategies 	<ul style="list-style-type: none"> • Involvement in focus groups • Written feedback • Interviews/ 1:1 conversations
Informing	<u>Communication of ACHA’s Work and Opportunities for Involvement</u> <ul style="list-style-type: none"> • Provide accessible information about ACHA’s aims and purpose work, avoiding jargon • Advertise opportunities for involvement • Communicate the impact of ACHA’s projects 	<ul style="list-style-type: none"> • ACHA website • Social Media • Newsletters

4. Methodology and Activities (continued)

4.2 The Community Advisory Group

- Central to our PPIE strategy is the role of the Community Advisory Group (CAG); a forum at which patient and public voices will be actively promoted through conversations and in-person/online meetings. The CAG will include key participants such as patients, carers, public involvement leads and representatives from community organisations. In this space, members will use their knowledge, experience and stakeholder contacts to ensure the views of patients, carers and members of the public are captured and are used to advise ACHA's communications and support other teams within ACHA's assurance framework in how the local voice is embedded and valued in all aspects of developing and implementing research projects and education programmes.

4.3 Training and Education

- We are committed to ensuring that ACHA works with public contributors from a diverse and representative range of social, ethnic and economic backgrounds as we seek to ensure that our approach is relevant and impactful within the local community. To achieve this aim we will train our educators and researchers to increase their knowledge, skills and capabilities in ways that routinely embed inclusive PPIE practices into the activities of ACHA.
- We will work in partnership with the Joint Research Management Office Engagement Team, the Centre for Public Engagement and the Queen Mary University of London and Barts Health NHS Trust engagement community to support, train and educate our collaborators, staff and stakeholders.

4.4 Payment and Recognition

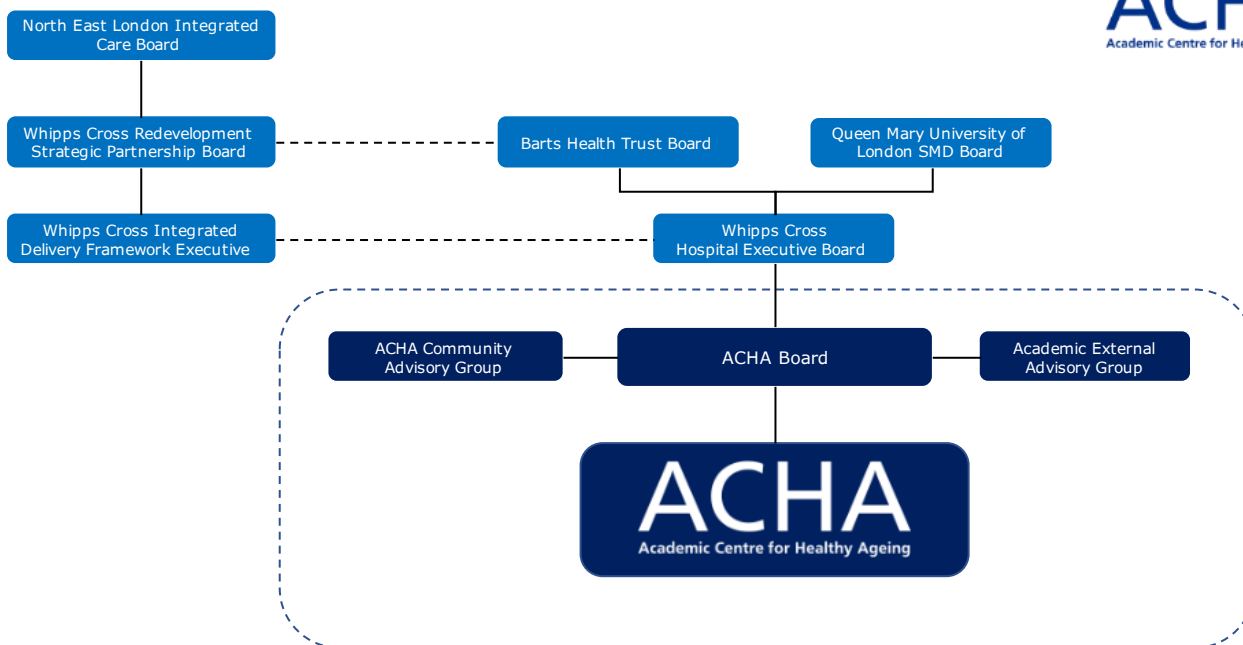
- We are keen to demonstrate our commitment to public involvement and our recognition of the value of public contribution to ACHA by recompensing participants for their time and input. Payment for public involvement supports and enables impactful participation, particularly when working with diverse populations.
- We intend to develop a comprehensive Public and Patient Recognition Payments (PPRP) Policy in line with the Barts Health NHS Trust and Queen Mary University of London approach to reward and recognition.
- This policy will comply with HMRC guidelines and consider public preferences for payment, for example, offering vouchers offers flexibility and minimises financial barriers.

5. Governance and Resource

5.1 Governance

A core objective of the 2023/24 ACHA Business Plan is the commitment to ensuring PPIE is fully embedded into the ACHA Governance Framework, so that key decisions are not made without input from the critical representation that is our patients, public and local community.

We have positioned the Community Advisory Group adjacent to the ACHA Board, to directly influence decision-making.



5.2 Resource

The ACHA corporate team includes a dedicated PPIE Lead, responsible for patient and public engagement and involvement, and working to ensure the patient and public voice is embedded throughout ACHA's work. The PPIE Lead will work closely with research leads and public contributors to implement an action plan to support the planning, delivery and communication of our PPIE Approach.

The action plan will include clear milestones that will ensure we engage with the local community as active members from the outset and thereafter throughout the research cycle to make our research relevant to local community and patient needs.

We are committed to ensuring that ACHA works with public contributors from a diverse and representative range of social, ethnic and economic backgrounds, as we seek to ensure that our approach is relevant and impactful within the local community. To achieve this aim we will train our educators and researchers to increase their knowledge, skills and capabilities in ways that routinely embed inclusive PPIE practices into the activities of ACHA.



6. Conclusion

Conclusion

- This strategy is designed to actively involve and engage patients and the public in the design, development and mobilisation of ACHA. For ACHA to have an impact, it is important that we develop a broad and holistic approach to understanding the priorities and perspectives of healthy ageing from the diverse communities within our local geographical area.
- ACHA will launch formally in Autumn 2024, requiring a refresh of this strategy to consider the strategic approach to research participation, which will reflect ACHA's research themes and the strategic priorities of our local community and health and care system in more detail.
- **We are keen to extend our thanks to our partners, local network engagement leads and the ACHA Community Advisory Group for their contributions to the development of the principles and the approach to PPIE outlined in this strategy.**

