



National Institute for Health Research (NIHR) Oxford Health
Biomedical Research Centre and Cognitive Health Clinical
Research Facility

Patient and Public Involvement, Engagement and Participation Strategy 2022 – 2027

With thanks to the public members of our Patients and Research Strategy Group for their support in developing this strategy.

1. Contents

1. Contents	1
2. Introduction	2
3. Vision and aims	3
3.1 Our vision is...	3
3.2 Aims	3
4. Resources	4
5. Objectives	4
5.1 Aim 1	4
5.2 Aim 2	6
5.3 Aim 3	7
5.4 Aim 4	7
5.5 Aim 5	8
5.6 Aim 6	9
6. Leadership, Monitoring, Evaluation and Impact	9
7. Further information	10
8. Glossary	11

¹The glossary of terms used in this strategy can be found on page 11.

2. Introduction

The NIHR Oxford Health Biomedical Research Centre (OH BRC¹) is a partnership between Oxford Health NHS Foundation Trust and the University of Oxford, working with 11 additional partner universities and NHS Trusts across England. Established in 2016, the OH BRC is one of only two centres in the UK that focuses entirely on mental health. After 5 successful years delivering cutting edge research and treatments in mental health and dementia, we were awarded a further £35.4m in funding from NIHR over the next five years, to support 11 research Themes focusing on mental and brain health.



Fig. 1 - OH BRC Themes 2022 – 2027

Involving people with lived experience of mental health difficulties (eg. patients, service users and their carers), as well as advocacy groups and members of the public, has been at the heart of our research. We recognise that only by working together can we innovate, ‘think outside the box’ and find creative approaches and solutions to develop better research that serves the needs and interests of patients and carers. To achieve this, all our 11 research Themes have a specific Patient and Public Involvement, Engagement and Participation (PPIEP) plan and allocated resource that allows their research to be carried out with patients and public contributors in a meaningful way, as well as a core PPIEP team that supports the Themes.

This document sets out the OH BRC’s strategy and framework for Patient and Public Involvement, Engagement and Participation (PPIEP) for 2022 – 2027. This is a joint strategy with the NIHR Oxford Cognitive Health Clinical Research Facility (CRF), which focuses specifically on early phase experimental clinical

¹The glossary of terms used in this strategy can be found on page 11.

research on mental health. In the programme of activities outlined below, there are activities specific to the OH BRC and others that will be executed jointly with the CRF. To distinguish between them we have assigned different 'action owners' to oversee delivery. This strategy was co-produced with our PAR (Patients and Research) Strategy Group and the CRF PPIEP lead.

3. Vision and aims.

The OH BRC mission is to improve mental and brain health through research, bringing together a multi-disciplinary team of researchers, clinicians and patients and public members to identify and tackle critical research questions. By strengthening communication between researchers and patients, caregivers, and members of the public, we will continue to ensure that our research is grounded in the lived experiences of those with mental health difficulties, and thereby leads to the development of diagnostics, treatments, and care that positively impact people's lives.

3.1 Our vision is...

To embed PPIEP into our ways of working, ensuring active involvement of patients, carers and members of the public in all aspects of our work, from research studies to funding applications and strategic decision-making.

3.2 Aims

The OH BRC strategy for PPIEP focuses on six strategic aims that align with the [UK Standards for Public Involvement](#):

1. Providing accessible and inclusive opportunities for involvement and co-production with public contributors to ensure our research benefits from fully representative PPIEP
2. Integrating PPIEP as standard practice across the BRC, by ensuring PPIEP is embedded in each research Theme and best practice and innovation is shared amongst Themes
3. Fostering meaningful involvement in research by creating support and learning opportunities for both contributors and researchers
4. Increasing the opportunities for public involvement in OH BRC governance, to influence the strategic direction of the OH BRC, ensuring that it remains transparent and accountable to its public members
5. Developing a cross-sector partnership plan that creates new partnerships, while building upon existing ones, to further improve PPIEP outcomes and processes
6. Conducting evidence-based and conceptually rigorous research on PPIEP and using these findings to stimulate innovation in PPIEP

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4. Resources

OH BRC PPIEP core team consists of an Academic Lead, a PPIEP Manager and a PPIEP Administrator. In addition, for each research Theme, there is a staff member responsible for the PPIEP activities of the Theme, and this person serves as a liaison between the Theme and the PPIEP core team.

The PPIEP core team and each of the research Themes possesses a specific budget allocated for involvement and engagement activities. The PPIEP core team budget will be used to: reimburse public contributors from the Strategic Advisory groups in accordance with NIHR guidelines; organise engagement activities with local communities; develop workshops and events to expand the pool of public contributors with lived experience of mental health difficulties; and provide training opportunities for researchers and public contributors.

Each research Theme PPIEP budget will be used by a Theme PPIEP staff member according to the Theme's workplan, which may include, but are not limited to, compensating public contributors for their time spent in preparing and attending meetings, disseminating results, and co-leading workshops.

5. Objectives

Each of the OH BRC aims are supported by a series of objectives. The work plan below demonstrates how actions, outcomes and timelines are connected to each objective and to the UK Standards for Public Involvement framework. We highlight three potential timeframes: "ongoing," which relates to activities that will be ongoing throughout the 5-year period, with an annual progress review in January; "short term," which involves activities that will be completed within 1-2 years; and "long term," which involves activities that will be completed within 3-5 years.

5.1 Aim 1

Providing accessible and inclusive opportunities for involvement to ensure our research benefits from fully representative PPIEP.

A. PAR, NeurOX YPAG, Older Adults and Diversity in Research groups: core PPI working groups to ensure comprehensive support for research across all OH BRC Themes	
Objectives	Timeframe Action Owner
1.1 Build on the existing contributor pool of people with lived experience of mental health difficulties, carers and public members with an interest in mental health so it is inclusive and diverse. Aiming to have a 10% average annual increase.	Ongoing Core team
1.2 Establish an Older Adults (>70 years) working group, with the support of the Dementia Theme PPIEP lead	Short term Core team
1.3 Develop relationships with our contributors and communicate their value to them <ul style="list-style-type: none"> - Dedicated PPIEP web pages updated regularly, with resources for the public - Email quarterly the wider contributor pool with a link to a featured piece on the OH BRC website - Organise quarterly 'meet and greet' sessions with researchers and public contributors with refreshments to thank contributors 	Ongoing Core team & CRF PPIEP team

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1.4 Involve in-patients and forensic patients in research <ul style="list-style-type: none"> - Working together with the Oxford Health NHS Trust service user involvement team to signpost, set up in-patients and forensic patients groups in mental health research 	Long term Core team
Outcomes to monitor: <ul style="list-style-type: none"> • Number, size and diversity of working groups, including development of the Older Adults group • Database monitoring: size and diversity of wider contributor pool, ie people with lived experience and/or interest in mental health research • Attendance and feedback of the 'meet and greet sessions' documented and evaluated • Number of hits on OH BRC PPIEP webpages 	
B. Identify goals and integrate diversity and inclusion objectives across the BRC	
Objectives	Timeframe Action Owner
1.5 Work with the Diversity in Research Group to identify barriers to involvement and participation in research by under-represented communities <ul style="list-style-type: none"> - Publicise Diversity in Research group work on barriers for involvement - Maintain iterative discussion on challenges for involvement - Identify and understand hidden diversity (e.g. disability, neurodiversity) - Co-produce and co-deliver approaches to overcoming these barriers 	Ongoing Core team (working together with Oxford BRC PPIEP team)
1.6 Build on existing partnerships with Blackbird Leys Community Development Initiative, Clockhouse and Oxford Community Action, three local communities that represent young people, older adults and minority ethnic groups exposed to social disadvantage and inequalities. Develop an involvement plan to expand the wider contributor pool of people interested in mental health research, within the first year. Monitor delivery and implementation annually	Short term Core team & CRF PPIEP team
1.7 In partnership with the University of Oxford Science Together programme , select one new local community and work with community leaders to create an engagement programme, using culturally appropriate and innovative methods (eg. arts) to develop relationships and introduce their members to research. The Science Together program connects with 5-8 new communities annually, fostering collaboration between communities and researchers to address community needs. Partnering with the Science Together team enables us to establish relationships with underrepresented communities in mental health research and actively involve them in our work.	Annually Core team & CRF PPIEP team
1.8 Produce clear and accessible communications, through co-production, using clear language. <ul style="list-style-type: none"> - Organise annual 'Writing for the public: deliver your message clearly and effectively' training for researchers and staff, and for (and with the help of) public contributors - Co-design dissemination materials to improve accessibility to research and foster involvement and participation of people from diverse backgrounds and with diverse needs, such as carers, people whose first language is not English and people with visual/hearing difficulties. These materials will be created in a variety of formats, including 'Easy to Read' versions where appropriate 	Ongoing Core team & CRF PPIEP team

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Outcomes to monitor: <ul style="list-style-type: none"> Barriers and enablers to involvement identified, solutions co-produced and changes implemented and documented Engagement and involvement with existing communities sustained and at least one new community relationship formed each year Attendance and feedback on training documented and evaluated 	

5.2 Aim 2

Integrating PPIEP as standard practice across the BRC, by ensuring PPIEP is embedded in each research Theme and best practice and innovation is shared amongst Themes.

Objectives	Timeframe Action Owner
2.1 Provide core infrastructure to support PPIEP across the Themes <ul style="list-style-type: none"> Review and implement a suite of documents to support Theme-specific and core PPIEP advisory groups (eg. Terms of Reference, Payment Policy, Confidentiality, Complaints procedures, etc) Create an accessible/ Easy to Read 'Toolkit' for PPIEP contributors with these policies Develop templates for reporting on PPIEP activities Develop templates for collecting feedback and feeding back to public contributors 	Short term Core team & CRF PPIEP team
2.2 Establish a 'PPIEP champion pair' (a dedicated researcher or staff member and a public contributor) for each Theme to support the delivery of Theme PPIEP objectives	Short term Theme Leads supported by core team
2.3 Support the PPIEP Theme lead to create dedicated, Theme-specific PPIEP advisory groups; making sure to signpost for other opportunities at the core (eg. sign up for wider contributor pool mailing list)	Short term Core team
2.4 Support the PPIEP Theme lead to create a programme of activities and deliver PPIEP within the Theme, which may include: <ul style="list-style-type: none"> Organise regular meetings with the researchers within the Theme Review current projects within the Theme, making sure PPIEP is present or highlighting the need for PPIEP when appropriate 	Short term/ Ongoing Core team
2.5 Foster communication between Themes <ul style="list-style-type: none"> Establish the 'PPIEP Champion pairs working group', comprising the 11 Theme PPIEP champion pairs and the PPIEP Manager. This group will meet quarterly to ensure robust communications across Themes, documenting activities, sharing best practice and brainstorming solutions Creating a mailing list for the PPIEP Theme Leads & core PPIEP team Drop-in review/ feedback sessions 	Short term/ Ongoing Core team
Outcomes to monitor: <ul style="list-style-type: none"> Frequency of researcher engagement with wider contributor pool and evaluation of this engagement (ie. were improvements to research achieved, and how they were achieved) Development and uptake of policy/governance/ guidance documents Presence of PPIEP champion pair for each theme and Theme-specific advisory groups, when appropriate Reporting of activities and shared learning with PPIEP Champion Pairs working group 	

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- Attendance and qualitative feedback on review and feedback sessions

5.3 Aim 3

Fostering meaningful involvement in research by creating support and learning opportunities for both contributors and researchers.

Objectives	Timeframe Action Owner
3.1 Establish PPIEP drop-ins for researchers to provide practical support for grant applications, advise on PPIEP implementation and problem-solve issues.	Ongoing Core team
3.2 Continue our successful pilot PPIEP grants scheme, whereby researchers can apply for small grants to support PPIEP consultations. Applications will be reviewed by public contributors from the PAR Strategy group.	Ongoing Core team
3.3 Enable and/or increase access to existing resources for training for researchers and public contributors (eg. University of Oxford PPIEP guidance for researchers and 'Introduction to PPIEP' online sessions for public members)	Short term/ Ongoing Core team & CRF PPIEP team
3.4 Create bespoke training to address unmet and emerging needs, in partnership with PPIEP colleagues within the University of Oxford, Oxford's NIHR infrastructure and Oxford Health NHS colleagues	Long term Core team & CRF PPIEP team
3.5 Develop culture competence training to provide researchers and staff members with the necessary tools to engage effectively with diverse populations and promote equitable and diverse research practices.	Long term Core team & CRF PPIEP team
3.6 Develop a peer-to-peer training program for young people, co-created by young people, with the youth organization Boing Boing	Long term Core team
Outcomes to monitor: <ul style="list-style-type: none"> • 1:1 support provided by the PPIEP Manager to researchers (number of studies, stage of research, form of support) • Number of successful grant applications • Number of grant applications with public contributor co-applicants • Number of training activities developed, provided and feedback 	

5.4 Aim 4

Increasing the opportunities for public involvement in OH BRC governance, to influence the strategic direction of the OH BRC, ensuring that it remains transparent and accountable to its public members.

Objectives	Timeframe Action Owner
4.1 Establish a PPIEP Operations working group 'PPIOG', composed of members of our core advisory groups, the core PPIEP team, a steering committee member and a PPIEP champion pair (on a rotational basis, to provide equal opportunities to the 11 Themes). This group is responsible for monitoring and assessing progress on the strategic objectives, sharing good practice, and raising any issues arising from PPIEP activities at Steering Committee	Short term/ Ongoing Core team
4.2 Establish reporting procedures that prioritise PPIEP at senior level <ul style="list-style-type: none"> - PPIEP Manager reports regularly at Theme Leads meetings, Partnerships Board and Steering Committee 	Short term/ Ongoing Core team

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- PPIOG members present annually to the Theme leads meeting on the overall progress of our PPIEP programme of activities	
4.3 Include the patient co-Chair of the PAR Strategy group on the Steering Committee, ensuring that patient perspectives and priorities are represented at the highest level of decision making within the OH BRC.	Short term/ Ongoing Core team
Outcomes to monitor: <ul style="list-style-type: none"> Establishment of PPIOG membership, schedule of meetings and terms of reference Production and presentation of the annual report at the Steering Committee Attendance and representation of public contributors and PPIEP staff at senior level 	

5.5 Aim 5

Developing a cross-sector partnership plan that creates new partnerships, while building upon existing ones, to further improve PPIEP outcomes and processes.

Objectives	Timeframe Action Owner
5.1 Continue collaboration with the Oxford Health CRF, designing, improving, innovating and delivering the shared objectives of this strategy	Short term/ Ongoing Core team
5.2 Build and maintain relationships with partners in Brighton and Birmingham, who have extensive expertise in working with children and young people with complex needs and exposure to social disadvantage	Ongoing Core team
5.3 Build upon existing partnerships with Oxford's NIHR infrastructure, the University of Oxford and both Oxford NHS Trusts (Oxford Health and Oxford University Hospitals) to jointly develop and deliver projects, such as the ongoing PPIEP staff accreditation programme, funded by NIHR Centre for Engagement and Dissemination	Ongoing Core team
5.4 Work alongside colleagues in the Working Together Operational Group, which brings together organizations from across the Thames Valley and Milton Keynes areas with a shared interest in developing PPIEP to improve health outcomes	Ongoing Core team
5.5 Collaborate with the Oxford Mental Health Partnership, an organisation that brings together the Oxford Health NHS Trust and the Oxford-based mental health charities, to broaden the involvement in research of people with lived experience of mental health difficulties, co-produce training for public contributors, and explore possibilities for innovation in PPIEP.	Ongoing Core team
5.6 Collaborate with the University of Oxford Science Together Programme to engage with a minimum of one local underrepresented community every year, designing and implementing an outreach plan with the community leaders to create new and sustainable partnerships.	Long term/ Ongoing Core team
5.7 Participate in national PPIEP networks, such as the BRC PPIEP Leads network	Ongoing Core team
Outcomes to monitor: <ul style="list-style-type: none"> Implementation of the joint objectives with the CRF PPIEP team Completion of the PPIEP staff accreditation pilot programme Evidence of sustained engagement with Blackbird Leys Community Development Initiative, Clockhouse and Oxford Community Action, creation of new involvement opportunities and growth of the wider contributor pool Development of new partnerships with local communities via the Science Together programme Monitor the diversity of patient and public groups in line with OH BRC EDI strategy. 	

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5.6 Aim 6

Conducting evidence-based and conceptually rigorous research on PPIEP and use these findings to stimulate improvements and innovation in PPIEP.

Objectives	Timeframe Action Owner
6.1 Utilise the diversity of the 11 OH BRC Themes as an evidence base, to compare and contrast methods and impacts of PPIEP across different areas of brain and mental health research	Short term/ Ongoing Core team
6.2 Contribute to evidence base for impact of PPIEP on research	Long term/ Ongoing Core team
6.3 Improve understanding of scope and limits of PPIEP to avoid tokenism and help identify and disseminate more effective PPIEP methodologies	Long term/ Ongoing Core team
Outcomes to monitor: <ul style="list-style-type: none"> Annual survey completed by Theme leads and/ or PPI leads within the Theme to evidence the impact of PPIEP in their research PPIEP research results documented and shared using both informal and formal (peer reviewed papers) methods 	

6. Leadership, Monitoring, Evaluation and Impact

The PPIEP strategy is overseen by the PPIEP Academic Lead and the OH BRC Director, who are accountable for achieving its goals. The PPIEP Academic Lead is primarily responsible for implementing the strategy and conducting evidence-based PPIEP research. The PPIEP Manager reports to the PPIEP Academic Lead and is responsible for the strategy's operational delivery.

To monitor the progress of the PPIEP strategy and contribute to the development of the annual report, we have established the "PPIEP Operations Group," which is made up of representatives from advisory groups, research Theme PPIEP Champion pairs, and the core PPIEP team. We will continuously seek feedback and conduct informal and/or formal evaluations to improve our practices. Additionally, we will commission an independent formal evaluation halfway through the OH BRC contract to assess and guide our performance.

To evaluate the effectiveness of our strategy and measure the impact of our programme of activities, we will use the following metrics:

- the growth of our contributor pool, ensuring involvement and inclusion of a wide range of backgrounds and lived experience of mental health difficulties
- the number of studies supported by PPIEP working groups
- the number of publications co-authored with public contributors
- the number of co-produced successful grant applications
- the number of grant applications that include PPIEP contributors as co-applicants
- evidence of impact of PPIEP activity on research methods and/or outcomes

Updates on the progress of PPIEP and its impact are regularly shared at the Theme Leads meeting, Partnerships Board, and Steering Committee. The annual report is also presented at these meetings to

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provide a comprehensive overview of the PPIEP strategy's accomplishments, and published on the OH BRC website.

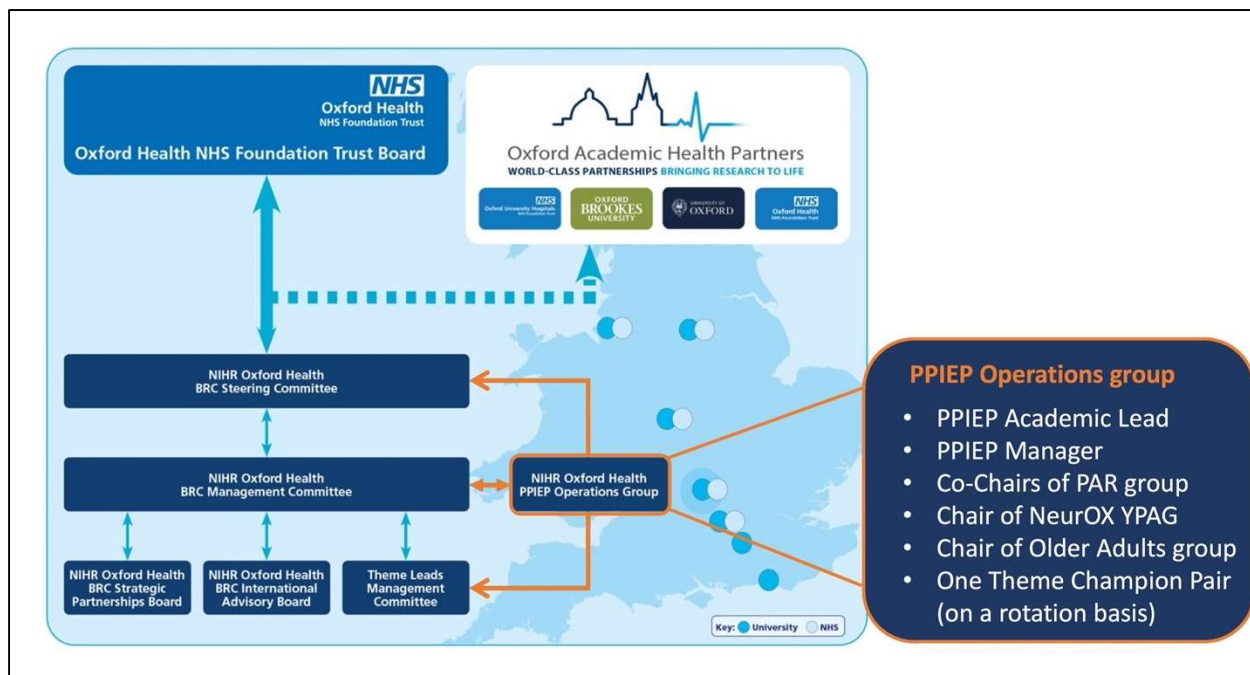


Fig. 2 – OH-BRC Reporting Structure. PPIEP is represented at various levels, advising, and providing feedback at various levels: BRC Theme Leads Committee, BRC Management Committee and BRC Steering Committee.

7. Further information

For more information about this strategy and how you can get involved in PPIEP for the NIHR Oxford Health Biomedical Research Centre please contact:

- Prof Edward Harcourt, PPIEP Academic lead: edward.harcourt@philosophy.ox.ac.uk
- PPIEP Manager: involvement@psych.ox.ac.uk

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8. Glossary

Terminology

Co-production in research

From INVOLVE guidelines & NIHR EDI strategy

Co-production is a collaborative approach in which researchers, practitioners and the public work together on a research project, from the start to the end. It involves active participation, shared decision-making and responsibility among all stakeholders. Co-production emphasizes the value of diverse perspectives, knowledge and resources to achieve higher quality and more impactful research, focused on the needs of those who will ultimately benefit from it.

Diversity

Being reflective of the wider community. Having a diverse community, with people from a broad range of backgrounds represented in all areas and at all levels.

Engagement

Engagement is where information and knowledge about research is provided and disseminated to the public, for example science festivals, open days, media coverage.

Equality

Ensuring that everyone is given equal access to resources and opportunities to utilise their skills and talents.

Equity

Trying to understand and give people what they need to achieve their potential; promoting notions of fairness, justice, entitlements and rights.

Inclusion

An approach where groups or individuals with different backgrounds are welcomed, culturally and socially accepted, and treated equally. Engaging with each person as an individual. A sense of belonging that is respectful of people for who they are.

Involvement

Involvement in research refers to active involvement between people who use services, carers and researchers. Involvement is often described as research that is carried out 'with' or 'by' patients, carers and public contributors, rather than 'to', 'about' or 'for' them.

Participation

Participation is when the public takes part in a research study, for example people being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.

Under-represented groups in research

Under-represented groups in research refer to groups or communities that are not adequately or proportionately represented in research. These groups often face limited visibility, access, or opportunities compared to the majority or more privileged groups. They may include marginalized communities based on factors such as race, ethnicity, gender, sexual orientation, socioeconomic status, disability, or other characteristics. Recognizing and addressing the needs and perspectives of underrepresented groups promotes fairness and inclusivity, resulting in research that is more equitable and inclusive overall.

Acronyms

BRC

Biomedical Research Centre

CRF

Oxford Cognitive Health Clinical Research Facility

EDI

Equality, Diversity and Inclusion

NIHR

National Institute for Health and Care Research

OH BRC

Oxford Health biomedical Research centre

PAR

Patients and Research Advisory Group

PPIEP

Patient and Public Involvement, Engagement and Participation

PPIOG

PPIEP Operations working group

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