

Welcome Pack for Patient & Public Involvement Representatives





We are delighted that you have joined us

Welcome to your new role as a Patient & Public Involvement (PPI) representative. We are delighted that you have volunteered in this way and everyone involved in our research appreciates your willingness to help, and the time & effort that you will put in. We hope that you will find the involvement interesting and rewarding. We hope that this Welcome Pack will answer the questions that you have and help you and the project(s) you work on to get the most out of your contribution.

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Introduction to patient & public involvement

Patient & Public Involvement (PPI) is a priority for both the Nuffield Department of Primary Care Health Sciences (NDPCHS) and the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford. We aim to develop strong public involvement in research, innovation and service improvement in the Thames Valley.

Within the Department of Primary Care and the CLAHRC some staff spend their whole time doing research, whereas others carry out research alongside other roles, such as being a GP, nurse or other health care professional.

We are developing a range of opportunities for Patient & Public Involvement in the management of both organisations, to complement the huge range of ways to be involved in the research projects that already exist in both organisations. Full details of all research projects are available at;

<http://www.phc.ox.ac.uk/research>

<http://www.clahrc-oxford.nihr.ac.uk/research>

Both organisations work closely with their partners in health research and health care provision across the region to try and ensure similar policy and procedures for all working with PPI in the Thames Valley. This includes the Oxford Clinical Research Network, the Oxford Academic Health Science Network and the Oxford Biomedical Research Centre.

Much of the research in Oxford is done jointly with other universities from around the country and occasionally overseas.

PPI Team

The team is led by Dr Sian Rees, Director of the Oxford Health Experiences Institute and assisted by Lynne Maddocks, PPI Coordinator.

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What does Primary Care research do?

'Primary care' is the first point of contact people have with the health care system. In the NHS, the main source of primary health care is general practice; your GP.

Primary Care research rethinks the way this healthcare is delivered to people, helping them to manage their own health and reduce the numbers that need to be admitted to hospital.

- * evaluates how effective services are
- * identifies people at risk of getting ill and helps to prevent illness
- * tests treatments to make sure they are safe and effective
- * identifies health and social inequalities
- * improves treatments and services
- * improves the environment, health and wellbeing of a local population
- * identifies the best use of resources
- * finds out what people think about services
- * ensures services and treatments are relevant to the public

What is Patient & Public Involvement in research?

Involvement in research means considering what research is to be done, how it will be done, how patients will be recruited and how the results may be used.

It is not taking part in clinical trials. This we call participation in research.

All of these groups of people will be described as PPI representatives;

1. Patient = current or recent users of health services
2. Public = interested citizens who will have some level of engagement with the NHS, in the sense of being registered with a GP, but they do not have and have not recently had serious health problems.
3. Carers = family and friends of people living with an illness, disability or long-term condition which means they cannot manage without support. Carers will have their own experience of health services provided to the person they support.
4. Voluntary sector representatives = staff of charities and community groups that support people with health problems and can represent the broad range of issues that their clients raise with them. Examples of this would include the Alzheimer's Society, Macmillan Cancer Support etc.

For this document the terminology chosen is PPI representative. However, this is one choice amongst many and there is no one term that is correct or even preferable. Other examples include lay member, patient advocate, citizen partner, research consultant, expert by experience etc.



As a member of the public, a specialised knowledge of research is not needed in order to be involved in it.

What is important is that you are able to bring your own knowledge and experience to the research process, whether as a patient or from your work and personal life.

We will provide you with enough information about research to be able to contribute comfortably.

What can you contribute?

It is worth being aware that the reason that you got involved may not be the same as that of other people who get involved.

People get involved because they:

- have personal knowledge and experience which they would like the research to take into account
- want a chance to give something back and help influence research to benefit others
- are frustrated about how they or others have been treated and welcome the chance to channel those negative experiences into something potentially more positive
- would like the opportunity to develop personal skills by learning about research, generally gaining experience and confidence and also receiving payment
- want to help bring about improvements to health and social care services and treatments for themselves and others
- want to help bring about improvements to the environment, health and wellbeing of their local community
- are altruistic and are pleased to give their time to do something useful

This website compiles video interviews and has a lot of information about what experienced Patient & Public Involvement representatives have to say about their involvement in health research:

[Health talk on PPI](http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics) OR

<http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics>

How does patient & public involvement work?

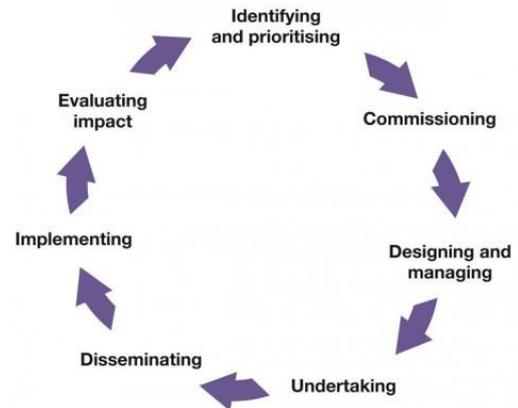
You could be involved in helping **to identify and prioritise** research so that you influence what will be researched. You will be able to ensure that the research priorities set are the same as those of the people who have the condition being researched or use relevant services.

You could be involved in **commissioning** research. This means deciding what research will be funded and making the arrangements to ensure that best value for money approaches are agreed with the funder.

You could be involved in the **design** of research helping to ensure that the research is relevant to people's needs and also that the research question and outcomes are clear.

You might get involved in **undertaking** the research such as:

- undertaking library-based research
- carrying out interviews
- running focus groups
- developing research tools and information
- gathering and reviewing documentary evidence
- analysing and interpreting the results of research



You could be very helpful to the researchers in using your personal and professional contacts to ensure that the findings are widely **shared and disseminated**.

Your involvement in research can provide a route to **implementing** change and improvement in the issues that most concern people and so can lead to new improved services and changes in practice.

You could be involved in **monitoring and evaluating the project**.

How might your involvement help?

Your involvement can provide a route to implementing change and improvement in areas that concern people most and lead to new improved services and changes in practice. For example, you may help:

- identify what research is important to fund. This may be different from the research that commissioners or researchers think should be done
- influence the way research is planned, for example by working on the research proposal, and how it will be carried out
- improve the experience for people taking part in the research by influencing the way the research is carried out
- influence the outcome measures of a research study, by suggesting measures that are important to people who use services
- increase the number of participants who agree to be in the research by making sure they are given good quality information and are treated with respect
- make it more likely that the findings of research are provided in user-friendly ways and publicised widely so that the wider public get to hear about it

What we need from you?

We are grateful for all of your input. The following are some of the attributes we hope you can contribute:

- the ability to express your views confidently at meetings attended by a range of professionals
- the ability to keep asking questions until you get enough information or an explanation to understand fully what people are talking about
- a willingness to listen to, and consider, different views
- an ability to challenge current thinking in ways that are both creative and supportive



- the ability to manage and plan your own time
- the commitment to attend meetings as agreed
- the commitment to prepare for meetings by reading information, which will be sent to you 1 – 2 weeks in advance
- to give and maintain a firm commitment to keep our research confidential

The amount of time that you will be asked to give will vary widely between projects. However, this will be agreed with you at the start of your involvement and you should only agree to what you can provide.

What will you gain?

- An opportunity to influence world class research
- An insight into how primary health care research is carried out
- New skills for your CV
- Learning about why research matters and understanding more about the topic being researched
- The satisfaction of making a contribution and helping to improve services

What will we give you?

Training

You can expect to receive enough training to enable you to be fully involved in this work.

As part of this you should have an induction which will include some time with the main contact for the project you are joining.

The induction will include being given reading material or directed to relevant websites to give you adequate information about the project you are working on. It is our intention that each newly appointed PPI representative will receive written information that will give you confidence that you are going to be well supported in your role and will provide you with all the information you need to seek help.

This will cover the following areas;

- ✓ the project that you are going to be contributing to
- ✓ main contact person for you with their contact details and working hours
- ✓ how long the project will last
- ✓ what time commitment is expected of you
- ✓ where you will be asked to attend or what the arrangements are for remote involvement
- ✓ how any specific support needs you have will be met
- ✓ what reimbursement of expenses or payment for your time you may expect
- ✓ the process for having your expenses and/or payment made
- ✓ how you should leave the project if you wish to do so
- ✓ how your involvement will be reviewed
- ✓ what you should do if you are experiencing any problems

You will be offered more extensive training when it is available.



Expenses

Each project will reimburse your out of pocket expenses.

We pay expenses against receipts and encourage you to make claims as soon as possible after the event. You will be provided with information on how to claim for any appropriate expenses incurred

We strongly recommend that you keep a record of all expenses and when you claim for them and receive payment and that you read the Patient & Public Involvement Payment Policy.

Reimbursement

Some projects offer remuneration. You are completely free to accept or decline the offer. Please read the Patient & Public Involvement Payment Policy to understand your duties in terms of informing HMRC of any income from this.

If you have any questions about this speak to your main contact or the PPI Coordinator. We do not want payment to become a burden or worry. It is routine practice and should not cause you any difficulties.

Support

The support that you will receive from the project will vary depending on the nature of your involvement but will include things such as;

- ✓ being sent papers in good time before a meeting
- ✓ phone contact to answer your queries
- ✓ additional information to help you to contribute
- ✓ regular feedback on the progress of the project

We have a glossary to explain acronyms and some research jargon – please ask if you would like this document. We will try to avoid acronyms and jargon.

Review

Occasionally you should be given the opportunity to review how your involvement is going with your main contact. At the very least you should have this opportunity annually.

You should also expect to be given feedback on:

1. the outcomes of the research work
2. the outcomes of the PPI input into the research work

In both cases you should feel free to respond to this feedback.

Leaving a project

You are a volunteer and may leave the project at any time. As we value your input however, we would ask you to give us as much notice as possible if you intend to leave.

Project Completion

At the end of your project you should be given the opportunity to do some other involvement work if you choose. If this is not offered to you please contact the PPI Coordinator who is keen to ensure that your skills, knowledge and enthusiasm are not lost to research.



Acknowledgements

This document was produced by the PPI team with contributions from Tricia Carver, Derek Day, Margaret Glogowska, Bernard Gudgin, Peter Kirby, Nathan Hill, Carol Munt, Derek Shaw, Bob Vause, Martin Wood and David Yeomans who helped us with developing this welcome pack providing a public and researcher perspective and helping us to ensure we cover the kinds of information that people need, when first getting involved in research.

We welcome your views on how helpful or not you find this pack – please let us know how we could improve it.

Please contact your main contact on the research project you are linked to or the PPI Coordinator if you have any queries about your involvement.

Thank you!



'Top tips' for new public representatives

*(The following top tips have been copied from Kath Maguire, a former public representative at National Institute for Health Research Central Commissioning Facility:
http://www.nihr.ac.uk/CCF/PPI/Top_tips_for_new_public_members.pdf)*

Before a meeting

- * Spend some time reading and digesting what the research is about in the plain English summary
- * On thinking about the project consider
 - o Potential patient benefit
 - o Summary of PPI involvement and strengths (how active is it and at what stages?)
 - o What is being asked of patients, and is it practical?
 - o Financial considerations of PPI
 - o Key concerns
 - o Potential opportunities for improving PPI
 - o Any other issues

Make sure you have prepared a very short and to the point summary of your views, keeping the points you make clear and concise – so that your most important points can be summed up in a few sentences. Don't expect to be able to make all your points during a meeting so prioritise the most important before you attend.

At the meeting

- * If you have a more general issue, think about what may be the best time to raise it. At the start of the meeting? AOB [any other business] at the end? Is it worthwhile talking to the Chair first and letting them know you have something you want to bring up, asking them what would be the best time to do it?
- * Feel confident – you've been appointed because you have shown that you can and do speak appropriately to Patient & Public Involvement and protection issues. There's no need to over prepare, but be prepared!
- * Don't worry about being 'right'. It can be easy to play yourself down and think that the other professionals on the committee are all experts, therefore they know more than you. However, you're an expert at what it's like to be a patient, and the experiences & opinions that you bring are valid and worth sharing.
- * Remember that everyone is on the same side; there is no 'them and us'; if people don't accept your points it's not because you're a PPI member. It's because they disagree.
- * Try not to only reflect your own health experiences, but use those experiences to present more general points, that you believe have affected others too.
- * If sometimes you don't feel confident about speaking out, or asking what something means, remember that the non-PPI people round the table are specialists in their own field, and don't



necessarily feel confident themselves on speaking about all proposals or all aspects of a particular proposal.

- * What's presented as a medical problem may not be; try some lateral thinking to analyse it a different way.
- * Think about how you say things so that they not come across as a criticism of the group or the individuals within it. Start with any positives.
- * Remember communication is a two-way street which often involves both talkers and listeners with different levels of competence in these tasks. Sometimes you might have to listen harder, ask more questions or explain your own points differently.
- * Be succinct – sometimes more is less, particularly when there is a lot to get through and a lot of voices to be heard.
- * You're doing this because you want to; enjoy it, and stop doing it when it stops providing "job satisfaction".



Additional Information about research and our structures

More information about health research

Within the Department of Primary Care and the CLAHRC some staff will spend their whole time doing research, whereas others carry out research alongside other roles, such as being a GP, nurse or other health care professional.

Researchers usually undergo some kind of training to do research, but the type and length of training varies. Often researchers work together as part of a team with people with different backgrounds and experiences, and from different organisations.

Much of the research that goes on in Oxford is done jointly with other universities from around the country and occasionally overseas.

The different stages of research

One way of understanding research is to think about the different stages of research.

Members of the public can be involved in all these stages:

1. Designing the research – what is the research question and how will it be investigated?
2. Funding – how research is funded and applied for
3. Carrying out research – collecting information, analysing and reporting
4. Dissemination – communicating the research findings to a wider audience
5. Development – putting research into practice

1 Designing the research

A Research Question is a statement that identifies the phenomenon to be studied. A strong research idea should pass the “so what” test. What is the benefit of answering this research question? Who will it help (and how)?

A research focus should be narrow, not broad-based. For example, “What can be done to prevent substance abuse?” is too large a question to answer. It would be better to begin with a more focused question such as “What is the relationship between specific early childhood experiences and subsequent substance-abusing?”

To develop a strong research question some of these questions need to be answered:

- » What are the important research questions in this field? Has the James Lind Alliance worked on setting priorities in this field? (a non-profit making organisation which brings together patients, carers and clinicians to identify and priorities the top 10 uncertainties – or unanswered questions – about the effects of treatments which they agree are most important; www.lindalliance.org)
- » Has a great deal of research already been conducted in this topic area?
- » Has this study been done before? If so, is there room for improvement?
- » Is the timing right for this question to be answered? Is it a hot topic, or is it becoming obsolete?
- » Most importantly, will my study have a significant impact on the field?



2 Funding of research

There are various local and national organisations that fund health and social care research, for example:

- National Institute for Health Research (NIHR),
- Voluntary organisations (e.g. Joseph Rowntree Foundation, Macmillan Cancer Support, Alzheimer's Society)
- Research Councils (e.g. Medical Research Council)
- Industry (e.g. pharmaceutical companies)

Most funding in primary care research is spent on the salaries of researchers.

Research usually starts with decisions being made about what research needs to be funded. In some research programmes the topics for research are decided in advance by research commissioners. In other research programmes it is up to researchers to put forward proposals for specific research projects that they wish to undertake. This is called responsive funding.

Members of the public are increasingly getting involved in advising research commissioners and researchers about what broad areas of research should be funded.

Obtaining funding for research can be complicated. Often researchers have to compete for the money to carry out their research plans. To apply for funding, researchers usually complete a research proposal or research grant application form. The application form asks for specific information including a description of the research and why it needs to be done, information about who will be doing it, and a detailed estimate of how much the research will cost.

Research commissioners are increasingly asking researchers to include information about their plans for public involvement in the research.

Sometimes, members of the public work with researchers or take the lead in applying for funding for research that they are interested in.

3 Carrying out research

Once funding has been agreed the research may also need permission from an ethics committee and research governance before it can get under way.

Carrying out the research includes collecting information, for example by sending out questionnaires or interviewing people, analysis and interpretation of the information collected followed by writing up the findings of the research.

There are two main approaches to research

- Quantitative and qualitative research.

The choice of a quantitative or qualitative approach depends on the type of information that is needed to answer a question. It is not unusual for both approaches to be used as part of one research project. Both research approaches draw on a large number of different research designs and research methods.



Quantitative research tends to be large scale in its approach to the research topic as it aims to be representative of the group being researched. It focuses on numbers and asks questions such as – ‘how often?’, ‘how many?’ or ‘how much?’

These questions help for example to:

- collect measurements of people’s pain on a scale from 1 to 10
- record information about people’s diet and lifestyle habits.

Randomised controlled trials or systematic reviews are examples of research designs used in quantitative research. The information is collected through various research methods such as survey questionnaires, tests and observations. Statistical analysis is then used to make sense of the information collected in this way.

Qualitative research focuses on people’s attitudes, views and how they make sense of their experiences and the world in which they live. It asks questions such as ‘what does it mean?’, ‘in what ways?’ or ‘what does it feel like?’

Compared with quantitative research it explores aspects of a research topic in greater depth and usually with a smaller number of people.

It often involves asking people for detailed descriptions and explanations. For example:

- how would you describe your pain?
- what are your views on eating fruit and vegetables every day?

Qualitative research approaches sometimes draw on action research, emancipatory or participatory research designs.

Qualitative research methods include in-depth interviews, focus groups, diaries and videos, as well as observations. The information is analysed and reported in a non-numerical way.

An example of consultation in a randomised controlled trial

Ali Khalid and other researchers involved stroke patients and carers in the design of a randomised controlled trial, to test the benefits of giving people oxygen immediately after having a stroke. The researchers carried out focus groups and also asked the stroke patients and their carers to complete questionnaires. The researchers asked for their views on the importance of the study, the relevance and acceptability of different measures of the benefits of the treatment, (e.g. improved communication, mood, memory), and who they felt should give consent (agreement) for individuals to take part in the study (e.g. a doctor or carer).

They helped the researchers to identify important measures that are not usually looked at in studies, and gave them other information about how patients want to be treated when they participate in research.

An example of research conducted by a patient

Patsy Staddon, a service user researcher has carried out a four year research project in Bristol on women users of alcohol treatment services. This involved two parts, a) interviewing women who have or had alcohol problems, and b) interviewing GPs and alcohol treatment centre staff. Both sets of research were reported back to the local NHS Trust, the Primary Care Trusts, the service commissioners, local GPs and the alcohol treatment centres. She believes that to obtain good research results, service users must be involved at every stage of the research process including the idea and the design.



Patsy and the women interviewed went on to form WIAS (Women's Independent Alcohol Support), a support and social group for women in Bristol.

4 Dissemination – communicating the research findings

Dissemination involves communicating the findings of the research to a wide range of people who might find it useful. This can be done through writing reports and articles, giving talks, producing a DVD or audio tape on the research.

It is also very important to feedback the findings of the research to the research participants who took part in the study.

5 Development – putting the research into practice

If the findings of the research are to be implemented this is usually done by health care practitioners or managers.

However not all research is used or results in changes or developments to policy, services or treatments. Some of the reasons for this are:

- other information also needs to be taken into account when making decisions
- limits on funding prevent some research findings being put into practice
- sometimes the findings are controversial and agreement cannot be reached as to how to take them forward
- sometimes research does not provide the answers and more research is needed

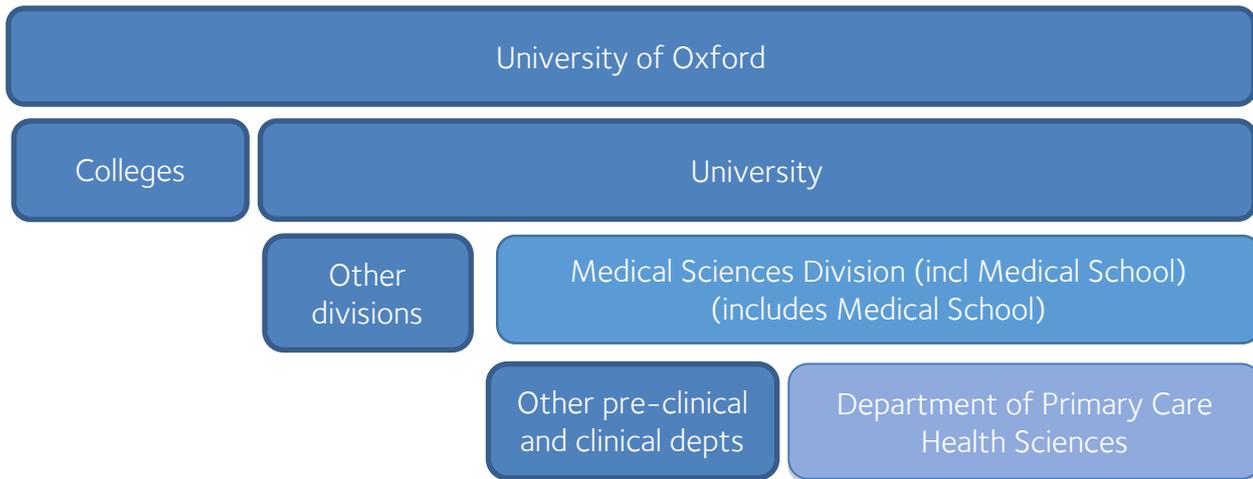
At the end of the research project, researchers may involve members of the public in monitoring or evaluating the research to see what it has achieved, as well as to help identify what questions remain, or new questions and topics that have arisen.



More Information about the Nuffield Department of Primary Care Health Sciences

The [Department of Primary Care Health Sciences](#) is one of the clinical departments that, together with pre-clinical departments, collectively forms the Medical Sciences Division in the University of Oxford.

University of Oxford Structure



We are an autonomous research department but we also contribute teaching to the undergraduate medical course and arrange placements for undergraduate medical students in GP practices.

We are a thriving and rapidly expanding department. Our research interests are in:

- Behavioural Medicine
- Cancer
- Cardiovascular & Metabolic Disease
- Centre for Evidence-Based Medicine
- Clinical Trials
- Infection & Childhood Disease
- Medical Statistics & Methodology
- Patient Experiences & Health Policy
- Primary Care for the Developing World

Oxford University is ranked the best in the country. The official UK-wide assessment of all university research, the Research Excellence Framework, found that Oxford has the country's largest volume of world-leading research in 2014.

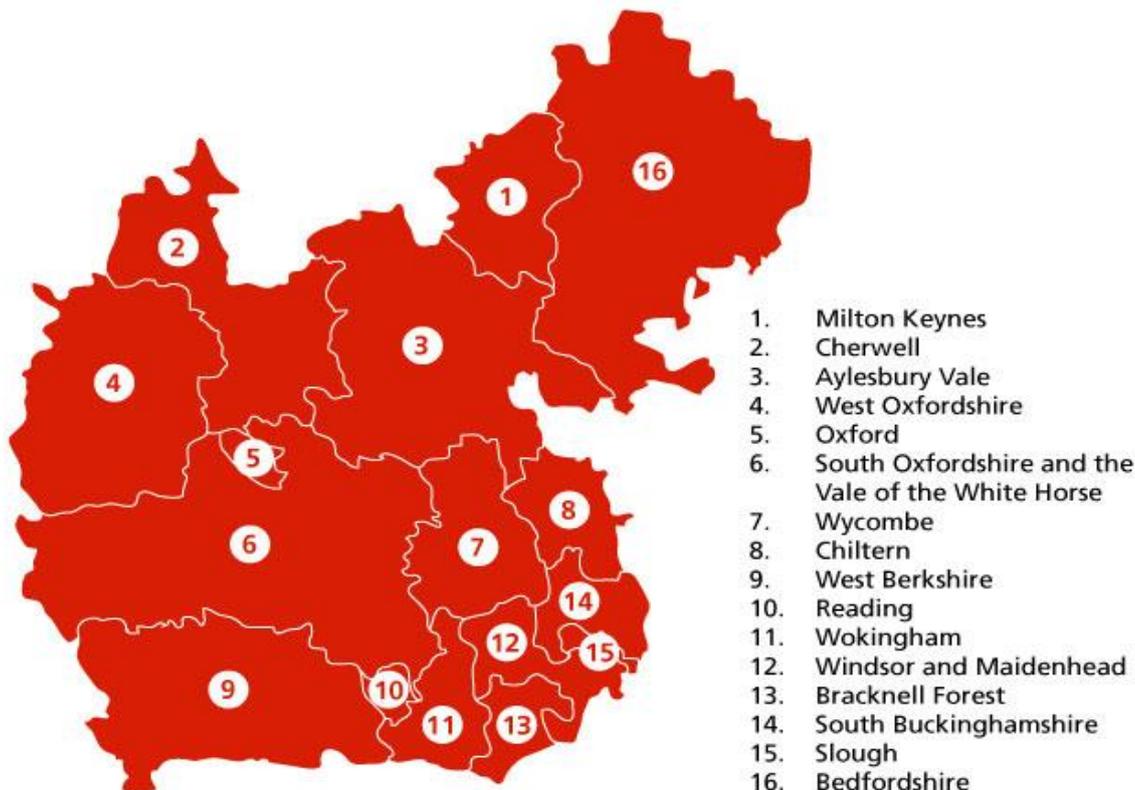


The Nuffield Department of Primary Care Health Sciences Head of Department is Professor Richard Hobbs who is also the Director of the NIHR CLAHRC Oxford.

More Information about the NIHR Oxford Collaboration for Leadership in Applied Health Research and Care (CLAHRC)

The [National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care \(NIHR CLAHRC\) Oxford](#) at Oxford Health NHS Foundation Trust, carries out ground breaking applied health research that will have a direct impact on patient health and well-being. We are a partnership between universities, health care commissioners and health care providers in the region of Oxford and the Thames Valley.

The NIHR CLAHRC covers Oxford and the Thames Valley and has been awarded £9 million of funding from the NIHR to ensure that the area's patients benefit from innovative new treatments and techniques. Additional matched funding from a variety of organisations including the University of Oxford, local Health Trusts, Care Commissioning Group's (CCG's), Local Authorities, Charitable Organisations, and Industry, have doubled the amount to make a total of £18 million available to fund research. With science excellence and strong collaborative leadership, the NIHR CLAHRC Oxford aims to address areas of high importance and relevance for patients as well as key NHS priorities: – the frail elderly presenting to acute medical services, people with dementia in care homes, and those with chronic enduring illnesses and comorbidities; the highest users of NHS services.





- **External partners**
- [Aylesbury Vale Clinical Commissioning Group](#)
- [Buckinghamshire County Council](#)
- [Chiltern Clinical Commissioning Group](#)
- [Health Education Thames Valley](#)
- [Oxford Academic Health Consortium](#)
- [Oxford Academic Health Science Network](#)
- [Oxford Brookes University](#)
- [Oxford University Hospitals NHS Trust](#)
- [Oxfordshire Clinical Commissioning Group](#)
- [Oxfordshire County Council](#)
- [Saïd Business School](#)
- [Thames Valley Local Area Team](#)

- **Oxford University Partners**
- [Department of Psychiatry](#)
- [Nuffield Department of Population Health](#)
- [Nuffield Department of Orthopaedics Rheumatology & Musculoskeletal Sciences](#)
- [Nuffield Department of Primary Care Health Sciences](#)
- [Oxford Institute Biomedical Engineering](#)
- [Radcliffe Department of Medicine](#)

Research themes of the NIHR CLAHRC Oxford

Theme 1: Early intervention and service redesign

We are innovating service delivery across partner NHS organisations and social care

Our research evaluates how new methods for delivering services in partner NHS organisations and social care settings are implemented. Our focus is on older people presenting to emergency medical units for assessment, people in care homes with dementia, and young people with a first episode of psychosis. Our expertise in health services research, trials, quantitative and qualitative methodologies, health economics and statistics guide the implementation of new service models, collect evidence of effectiveness, and analyse outcomes.

Working in partnership with Saïd Business School, we are also developing a series of training tools to build capacity and leadership skills across the NIHR CLAHRC Oxford and our partner organisations.



Theme 2:

Health behaviours and behavioural interventions

We are developing evidence to improve the management of back pain and other long-term painful conditions

Our research translates knowledge from clinical trials in lower back pain, chronic neurological conditions and dementia to provide better evidence, guidance and training to the general public, people with physical and/or cognitive disabilities, families and carers. We also target primary care, public health and rehabilitation practitioners and commissioners.

To improve the provision of services to care for people with comorbidity, our research aims to develop new joined-up services that deliver care for people with both physical and mental illness.

We are examining the prevalence and nature of comorbidity in specific groups of people and identifying the challenges to offering better care. Using the data collected from descriptive research methods, such as interviews with patients and healthcare staff, and systematic reviews of existing literature, we are constructing and piloting new services specifically for patients with comorbidity, ensuring they are feasible, acceptable and successful, and evaluating them in randomised controlled trials.

Theme 3:

Patient experience and patient reported outcomes

We are improving the responsiveness of local services to patient reports of experience and outcomes

Focussing on those with long-term conditions, our goal is to raise the quality of care by improving how local services respond to patient feedback of experience, and measures of outcome before and after a procedure or programme of care.

Research uses qualitative interviews and structured survey techniques to develop a Patient Reported Outcome Measure (PROM) for long-term conditions, in addition to testing PROMS in a primary care setting, and reviewing how impactful feedback can be. We will examine the scope for integrating new measures across health and social care.

We are working towards offering more effective methods to capture, process, synthesise and communicate evidence of outcomes and experiences at the level of the local health economy.

Theme 4:

Better management of medical–psychiatric comorbidity

We are developing new ways of caring for people with a mental illness associated with physical illness

Many people who have a physical illness also have a mental illness (termed medical–psychiatric comorbidity). This can lead to a poorer quality of life, worse health and increased cost of medical care. Healthcare services are often not designed to treat both illnesses in tandem.

To improve the provision of services to care for people with comorbidity, our research aims to develop new joined-up services that deliver care for people with both physical and mental illness.

We are examining the prevalence and nature of comorbidity in specific groups of people and identifying the challenges to offering better care.

Using the data collected from descriptive research methods, such as interviews with patients and healthcare staff, and systematic reviews of existing literature, we are constructing and piloting new services specifically for patients with comorbidity, ensuring they are feasible, acceptable and successful, and evaluating them in randomised controlled trials.



Theme 5:

Patient self-management of chronic disease

We are developing and testing technology to enable patients to manage their own long-term conditions

Enabling people with chronic disease to make day-to-day decisions about their own conditions can help them to live with the best possible quality of life and reduce their reliance on hospital resources.

Focusing on people with obesity, type 2 diabetes, chronic lung disease, gestational hypertension and bipolar disorder, we are developing and testing a series of technology-enabled self-management interventions.

For example, we are studying how women with gestational diabetes can measure their own blood pressure twice daily and text their results to health professionals rather than visiting their GP. We are also investigating how people with chronic obstructive pulmonary disease can utilise a tablet computer-based system to rate their mood, since there is increasing evidence that anxiety and depression go undetected and undertreated in people with this illness. Focussing on lower back pain and other painful long-term conditions, in addition to people with cognitive and physical disabilities who are referred for exercise in primary care, we are developing new insights into how to integrate exercise and physical activity alongside interventions for other health behaviours (in particular smoking cessation and diet). A multi-methods approach is used including systematic reviewing, randomised controlled trials, observational work and qualitative research.

Each of the projects within each theme will have its own Patient & Public Involvement element. This will vary in each case due to the nature of the work but might include one or two people on a trial steering committee or be an ad hoc focus group or an ongoing advisory group.