



Research Matters

NEWSLETTER SPRING 2017

noclor

RESEARCH SUPPORT

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First thoughts...

Welcome to the ninth edition of the Noclor newsletter, which includes news on the latest developments in mental

We report on **Dr Daniel Davis's** DELPHIC study (Page 4) on whether delirium accelerates the path towards dementia – taking the unique approach of monitoring patients as they move from their home, into hospital and back into the community – and on a major national study (Page 5) that has found that loss of navigational skills may be an early warning sign of Alzheimer's disease.

And we celebrate the success of the **R&D team** at West London Mental Health Trust (Page 12), a Noclor partner that has earned top spot in the North West London Clinical Research Network region for meeting the NIHR approval process target.

We hope you enjoy this issue, and we welcome feedback and suggestions for future issues (esther.tubone@nhs.net). Visit our website (www.noclor.nhs.uk) or follow us on Twitter (@NoclorResearch) for more research news and details of how we support the vital work carried out by our partner trusts in London.

Lynis Lewis, Service Director
NOCLOR RESEARCH SUPPORT

health research, cancer early warning systems, and links between genes and health.

Dr Kamaldeep Bhui (Page 8), an expert in psychiatry who was awarded a CBE in the 2017 honours list, talks about the controversial findings of his research into depression and radicalisation, which challenged prevailing views on terrorism.

As ever, many projects are busy recruiting. The **FORECEE** international study (Page 3) is seeking to develop the world's first early warning system for the four main female-specific cancers. And **Dr Mehul Mathukia** (Page 10) talks about his GP practice's involvement in a huge east London study seeking to understand why South Asians in the UK have poorer health outcomes than the rest of the population.

Professor Angela Hassiotis (Page 6) is profiled for the major contribution she has made to ensuring that intellectual disabilities are taken seriously.

Key Contacts

The Noclor Research Support team is here to help you with research. So please feel free to contact our various teams.

For queries relating to Research Management and Support:

contact.noclor@nhs.net

Funding and Finance queries:

finance.noclor@nhs.net

Looking for advice with or interested in a project in Primary Care? Contact:

primarycare.noclor@nhs.net

Keen to learn more about our free training courses, or to offer content suggestions for future Noclor publicity material? Contact:

esther.tubone@nhs.net

If you would like to get in touch with our Service Director, Lynis Lewis, please contact:

esther.tubone@nhs.net

Women's cancer study foresees early alerts

A prestigious international research study, led by UCL and supported by Noclor, is seeking to develop the world's first early warning system for the four most common types of female cancer.



The EU-funded FORECEE project, which is recruiting in London, Prague, Munich, Milan, Bergen and Southampton, provides free genetic testing for ovarian, cervical, breast

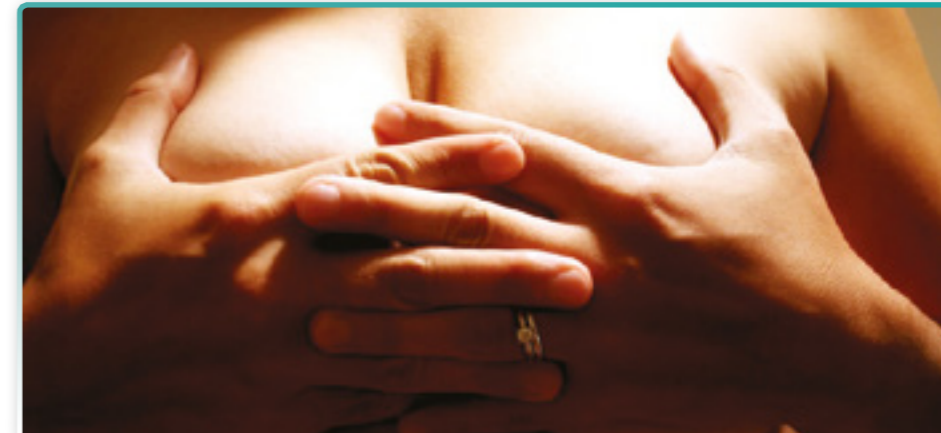
and womb cancers.

Tests being offered are not routinely available on the NHS, and would cost around £4,300 if obtained privately.

The aim is to determine accurately the risk that a woman with a BRCA1 or BRCA2 gene mutation will develop one of the cancers – and, most importantly, identify new ways to prevent them.

The research involves using epigenetics – the study of mechanisms that switch genes on and off – to search for indicators of future cancer.

It will change medicine very, very substantially.



Identifying risk factors will make it possible to give better advice to women about their options for staying healthy and preventing the development of the four cancers.

Ultimately, the aim is to develop a tool based on genetic, epigenetic and microbiome changes in cervical cells, as well as buccal and blood samples, to aid prediction and risk stratification of the four main women-specific cancers.

The project is a biosamples collection study, with healthy volunteers, BRCA mutation carriers, and women with gynaecological and breast cancer as the three main study groups.

● Anybody interested in participating in the study can follow this link to book an appointment directly at the study clinic: <http://www.brcaprotect.org/participate>

Making research everybody's business

Study aims to clear up confusion over delirium

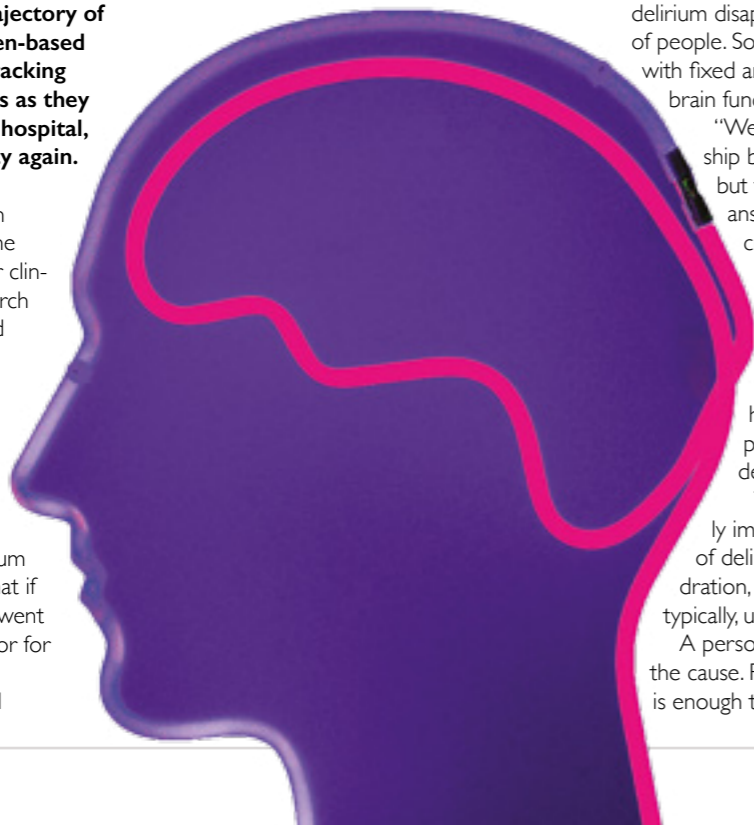
Does delirium accelerate the trajectory of dementia? That is what a Camden-based study is seeking to find out by tracking 2,000 people aged 70 to 100-plus as they travel from the community into hospital, and back out into the community again.

The Delirium and Population Health Informatics Cohort (DELPHIC) is the brainchild of Dr Daniel Davis, senior clinical researcher in the Medical Research Council Unit for Lifelong Health and Ageing at UCL.

The study – also known as LINKAGE (Long-Term Information and Knowledge for Ageing) – began monitoring participants in January this year and will complete its assessments in June 2020.

“It used to be thought that delirium was a consequence of illness, and that if you treated the illness the delirium went away,” says Dr Davis, chief investigator for the study.

“However, I observed that not all



delirium disappears 100% of the time in 100% of people. Sometimes, delirium is associated with fixed and new permanent changes in brain function.

“We already know there is a relationship between delirium and dementia, but the question the study is trying to answer is what level of delirium increases the likelihood of dementia.”

Delirium is characterised by changes in arousal, confusion and hallucinations. Both delirium and dementia are brain syndromes, but the former evolves over hours and days, whereas the latter progresses over months, years and decades.

The older and the more cognitively impaired you are, the higher the risk of delirium. It can be caused by dehydration, new medication, and infections – typically, urinary.

A person’s vulnerability determines the cause. For example, a minor infection is enough to trigger delirium in an elderly

person with dementia. For a young person without dementia, there would need to be a more major cause – such as meningitis, a road traffic accident, or major surgery.

The key issue is that anyone who has delirium must have a new medical reason for it.

Dr Davis says: “Studies have already been carried out on people with delirium in hospital, but this study is the first to assess the wider population in Camden.

“It will reveal how much cognitive deterioration is present at two years – compared with what would have happened anyway – and how much is in relation to the delirium episodes people might get in hospital.”

Participants will be monitored every day that they are in hospital, undergoing cognitive assessments and answering questions about memory, thinking and orientation. Davis and his colleagues will also look at blood tests and computerised tests of attention.

The information will then be related to the issues the participants had at the start of the study, when they were in their own homes, with a follow-up study two years later.

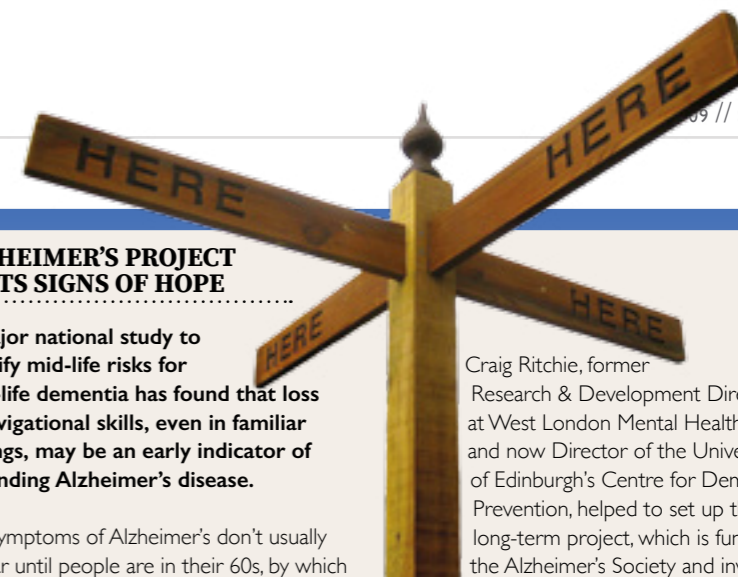
ALZHEIMER’S PROJECT POSTS SIGNS OF HOPE

A major national study to identify mid-life risks for later-life dementia has found that loss of navigational skills, even in familiar settings, may be an early indicator of impending Alzheimer’s disease.

The symptoms of Alzheimer’s don’t usually appear until people are in their 60s, by which time it has already done profound damage to the brain.

But the PREVENT dementia project, based at the University of Edinburgh and involving several other UK research centres, aims to detect signs of Alzheimer’s in people while they are still relatively young.

One of their preliminary findings is that people found to be at higher risk were poorer at tests that measured ability to visualise their position, and generally had a small hippocampus – a region of the brain that plays an important part in spatial navigation.



Craig Ritchie, former Research & Development Director at West London Mental Health Trust, and now Director of the University of Edinburgh’s Centre for Dementia Prevention, helped to set up the long-term project, which is funded by the Alzheimer’s Society and involves specialists from medicine, basic science and social sciences.

He says: “By understanding how the brain ages over time, it may be possible to detect the earliest stages of dementia before symptoms develop. We hope this insight will lead to the development of new treatments that could prevent the disease in those at risk.” Early identification can lead to lifestyle changes that help reduce the risk of the disease, and research may find that drugs currently ineffective would be beneficial if given during the disease’s early stages.

Grants help to make an intellectual impact

PROFILE: Angela Hassiotis, professor of psychiatry at UCL, explains how past setbacks have made her determined to ensure that intellectual disability is no longer stuck with a ‘Cinderella service’ tag

People are much more convinced these days of the need for evidence-based care in intellectual disability, but it certainly wasn't always like that. I know what it is like to spend two years trying to get a grant off the ground – and not succeeding.

That is a challenge, and you either ask yourself whether you are going to continue or be disheartened and stop trying. I have chosen to continue, and I think this is an important lesson for early-career researchers.

About 1% to 2% of the population has an intellectual disability. That might appear to be a fairly small percentage, but we only know about a fifth of those who might require services, so we miss out on a lot of individuals.

Our research in this field at UCL deals with a range of service user age groups, but my research and my clinical work is around adults with intellectual disabilities.

The harsh fact is that people who have an intellectual disability will have the disorder throughout their life.

There is a clinical involvement around transition, usually starting when children reach the age of 14 or so. They move to adult services at the age of 18, and we're then involved in cases where there are emotional, behavioural or health problems.

The main push for registering for services is when children start school, because they will need educational support.

However, by the age of 15 or so, often they have not done well in school, drop out of the education system, and are consequently lost to services. These are people with milder disabilities, but we tend to know about people with more severe disabilities.

We have recently received two important grants for research. One is for addressing early intervention for children aged three to five. The

second is for providing evidence for models of care for challenging behaviour, which is one of my areas of interest and expertise.

It is about underpinning what works well with science. We are going to use patient outcomes and the opinions of patients and other stakeholders to build a picture of what kind of services we should be providing.

This is important because, since the 1970s, there has been a lot of work on what a service might look like, but no one has been providing any evidence for either patient outcome or cost. Because of this, a service that might have been developed is then decommissioned, so there has been no continuity.

One of the reasons the area has been so far behind in terms of funders being aware of us is that epidemiological studies were few and far between, and those we have had were mainly from south-east London – the only place where any research was going on.

So I started to meet up with colleagues



within the professional networks to discuss ways we could further develop research ideas and capacity.

Early collaborations led to papers being published, and that's how I established myself. I was appointed as senior lecturer at UCL in 1999 and was successful in getting a seed grant.

My appointment meant establishing the Department of Intellectual Disability Psychiatry at the then Department of Psychiatry and Behavioural Sciences. With that came an increased awareness of intellectual disability.

I got involved in teaching the medical and postgraduate students, revising the curriculum, and ensuring that we were up to date.

I am proud of what we now have achieved here at UCL, and that our work is being taken seriously.

Clinically, I have trained a number of bright psychiatrists who have decided to go on to

become specialists – for example, consultants – in intellectual disability, and I see this as an important step in our speciality not only surviving but going forward.

We have been lucky that the Division of Psychiatry at UCL, Camden and Islington NHS Foundation Trust and the Camden Learning Disability Service have been prepared to listen and to work with us.

Healthcare commissioners are now more aware that they need to manage costs, and there is a drive from

the Department of Health and NHS England to improve the care of people with intellectual disabilities.

We are much more competitive and have been able to carry out multidisciplinary and interdisciplinary research, resulting in papers in high-impact journals. We have got things to say – and people are now listening.

“I am proud of what we now have achieved, and that our work is being taken seriously”

Making research everybody's business

Healthy approach to tackling radicalisation

Q&A: Kamaldeep Bhui, Professor of Cultural Psychiatry and Epidemiology at Queen Mary University London, talks about his controversial and game-changing research into links between depression and radicalisation



Q *How did it feel to receive a CBE in the 2017 New Year's Honours list.*

A It's nice that this work has been recognised, and good for the mental health sector as a whole. Tackling health inequalities and research on cultural aspects

of mental health care is not easily understood or resourced as it falls between two stools, or is seen as too specialist.

Q *How would you describe your work?*

A In cultural psychiatry, we deal with many variables, including culture itself and how it works as a process, cultural identity, belief systems and culturally-shaped behaviours – and how these can lead to better or poorer health generally, and mental health specifically.

Q *How did your study into depression and radicalisation come about?*

A It is particularly important to try to

understand what drives health inequalities, as this gives us clues to aetiology, prevention and treatment among the most multiply-disadvantaged people. Some of my work had already involved measuring the impact of religiosity, and, consequently, when the discussion about radicalisation and terrorism emerged after 9/11 in the US, and after the 2005 bombings in London, the research variables that were being proposed as influential were ones that

I had already been developing, testing and using in epidemiological and health systems research. It seemed to be a natural transition for me to work on radicalisation.

In cultural psychiatry circles, tackling religion, culture, identity and culturally-shaped health beliefs, and links with violence are not unheard of. But for most people working in mental health settings, at that time at least, it was unusual territory.

Q *How did you approach the study?*

A We came at the problem from a public health perspective. What we were not doing was dealing with terrorist offenders and those already convicted of terrorism. We needed to understand the pathways to radicalisation, so we looked at early phases by applying a public health

‘When we first published the finding in 2014, the popular press and newspapers reported them in a frenzy’

approach, which is relatively uncommon in the UK but is being applied in the US, Canada and other countries – not only to terrorism but also to violence in general.

The research was grounded in trying to better understand why people develop extremist beliefs, and whether this was related to what was popularly portrayed: discrimination, isolation, poor health, inequalities in the community, a feeling of being disconnected.

As part of the research, I developed a measure of radicalisation and tested it. This was only

possible by working in close association with communities and ensuring good patient and public involvement (PPI).

What we found was that it was not discrimination or poverty or unemployment that seem to be correlated with higher levels of extremism, but being reasonably wealthy, well educated and experiencing relative social isolation.

We also found that those who had poor health, and migrants, who were often targeted as potential perpetrators, were less likely to have extremist sympathies. Depressive symptoms seemed to emerge as a positive correlate of extremist sympathies, but we have much to do to explore this association.

Inequalities are linked with depression, so we thought they would be linked with extremism. Surprisingly, it seemed they weren't particularly. We are still trying to investigate what that means.

Q *How has the research made a difference?*

A First of all, I provided empirical evidence when there was very little. Portrayals of radicalisation and its drivers were based on retrospective biographies of convicted terrorists being applied to whole populations in a way that is scientifically flawed.

Second, I provided a way of measuring extremism.

Third, because the findings challenged popular but flawed views that discrimination was a driver of extremism, we talked to policymakers in the UK, Canada, Norway and the EU. Essentially,

policy had to shift to reflect the findings.

We advocated the need to better understand how young people and young adults think about and respond to extremism and conflict, and to encourage prevention at the earliest stage possible.

We were the first in the UK to make this a public health issue, and it has led to calls for health practitioners, social care workers, teachers and all other public servants, and the public

in general, to be actively thoughtful and involved in the process.

Q *How were the findings received?*

A When we first published the findings in 2014, the popular press and newspapers reported them in a frenzy, and the reports were not always accurate. There had been concern that existing counter-terrorism policy was making people who wanted to be part of the solution feel like suspect communities.

Our work was carried out with the communities and by talking to people of Muslim heritage – Pakistani and Bangladeshi – and they were universally in support of the research. Our work brought the communities in because we grounded it in everyday experiences and had good PPI all the way through.

Q *How have you made use of the research?*

A Having developed the instrument, we have just completed a study on white British and Pakistani men and women in three towns, repeating the methodology but using better measures of depression, to see if the instrument stands up to scrutiny in a different population. We will also use other measures of potential drivers of extremism, such as personality difficulties and criminality, which have not been properly tested in a population.



Making research everybody's business

Family GPs boost South Asian genes study

The Mathukia GP surgery in Redbridge, northeast London, is leading the way in a groundbreaking study that seeks to discover why South Asians have some of the highest rates of poor health in the UK

Pakistani and Bangladeshi communities in the UK suffer twice the average number of deaths from heart disease, five times the average number of deaths from type 2 diabetes and generally have poorer health than people from other groups. People in these groups are also much more resistant to current treatments.

To try to understand why, Barts Health NHS Trust and Queen Mary University of London have set up a huge study – the biggest of its kind – into the link between South Asian genes and health. By 2020, they are planning to recruit 100,000 patients from east London who are of Pakistani and Bangladeshi origin.

Dr Mehul Mathukia, a clinical director at Redbridge Clinical Commissioning Group – a Noclор partner – and a GP champion for Noclор, runs a practice with his father and brother in Redbridge, where there are a large number of patients of Pakistani and Bangladeshi origin. The practice has recruited 600 patients for the study, the highest number of any of the practices involved so far.

“The idea is to create a genetic databank to try to identify whether there’s a specific type of gene that predisposes Pakistani and Bangladeshi patients to conditions such as diabetes, hypertension and heart disease,” he says. “If the study is able to identify specific genes, we can target medications and treatment towards those genes. It potentially has massive consequences for future generations in terms of improving their health and outcomes.” Dr Mathukia puts his practice’s recruiting success down to team effort. “We allowed one of the researchers to

be based in our surgery to approach patients in our reception area,” he says. “We trained up our reception staff so that they were able to signpost patients, clinicians advertised it, and we put posters up and provided leaflets.”

Participants are asked to give a saliva sample, complete two forms and allow researchers to access their medical records. Some volunteers will be asked to partake in further assessments. The study team will use this information to build up a picture of the genetic makeup of the two communities. The databank will also mean patients can be more easily recruited for future studies.

“It’s good to be able to contribute to the future development of medicine and medical science,” says Dr Mathukia. “It’s a really worthwhile study because it’s something that we observe in our daily practice: that these patients tend to have much worse health outcomes, much worse quality of a life as a result of that and much poorer life expectancy.”

For more information on the study, visit <http://genesandhealth.org>.

SERIOUS MENTAL ILLNESS LINKED TO HEART DISEASE



An international study spanning four continents and data on 3.2 million people has shown that

the risk of premature death from cardiovascular disease is 85% higher in people who have a serious mental illness (SMI). The researchers found that people with SMIs such as schizophrenia, bipolar disorder and major depression were up to 78% more likely to suffer from damaged hearts and arteries than healthy individuals.

Dr Brendon Stubbs, a research physiotherapist and member of the international research team at King’s College London, says: “These findings are a stark reminder that people with SMI are being left behind, at a time when the health of the general population appears to be benefiting from public health initiatives to reduce the burden of cardiovascular disease.”

HIGH RISE IN PRESCRIPTION OF ANTIDEPRESSANTS BY GPs

New analysis of NHS data has revealed a seven-fold increase in the number of antidepressants prescribed by GPs in England in the last quarter of a century. Researchers found that more than 64 million prescriptions were issued in 2016 to treat conditions such as clinical depression, obsessive compulsive disorder, anxiety, and post-traumatic stress disorder. In 1991, the number was just 9 million. Data for different regions showed that twice as many antidepressants are prescribed per person in the north east of England as in the south east and London.



Making research everybody's business



West London R&D team builds winning system

Hidden away in a corner of Southall, west London, a small team of dedicated research staff is making a big difference.

West London R&D has outperformed all other trusts in the North West London Clinical Research Network region on the 40-day NIHR target for completing the approval process for funded research.

Two research co-ordinators and one R&D facilitator, overseen by R&D manager Angela Williams, have been supporting research at the West London Mental Health Trust – a Noclор partner – for more than 10 years.

They help to guide studies through the NHS approval process, and to ensure that research at the trust complies with governance requirements.

The team offers assistance and guidance on all aspects of research projects and at every stage of a study's lifetime, from the initial feasibility assessment, right up until the study closes.

● Members of the team would be delighted to help you obtain confirmation of capacity and capability for any research you'd like to conduct in the Trust just drop us a line at research@wlmht.nhs.uk

'I like meeting researchers and providing support and advice in the feasibility stage of their studies'

Alene Pointon, R&D Facilitator, conducts feasibility assessments for mental health research across clinical research domains. She ensures that any barriers to research are identified through early engagement with sponsors and chief investigators.

● Contact:
Alene.Pointon@wlmht.nhs.uk



'I enjoy helping and supporting researchers through the stages of the study lifecycle'

Ruby Choudhry, R&D Co-ordinator, and first point of contact for all funded research that takes place at West London Mental Health Trust. She deals with all study-related queries, sets up the studies at the trust, and approves them.

● Contact:
Rubina.Choudhry@wlmht.nhs.uk



'It's good to see how researchers' protocols develop by going through our peer review'

Maria Tsappis, R&D Co-ordinator, supports researchers carrying out student or unfunded research. She ensures that their research meets the appropriate scientific standards to gain approval from West London Mental Health Trust.

● Contact: Maria.Tsappis@wlmht.nhs.uk



Making research everybody's business

Pathways to training opportunities

July training courses

The following sessions are being hosted by Noclor and our associates. All the sessions are free and open to all staff who have an interest in research (including doctors, dentists, nurses, research assistants), and who are working in or associated with our partner Trusts.



Monday, 24 July 13:00-17:00	Tuesday, 25 July 09:30-17:00	Wednesday, 26 July 13:00-17:00	Wednesday, 26 July 17:30-19:00	Thursday, 27 July 09:30-13:30
Good Clinical Practice in Research	Essential Skills for Clinical Research Nurses	Informed Consent in Clinical Research	Principal Investigator in Research	Setting up and Managing the Trial Master File
This course addresses the underlying principles of GCP and is not confined to GCP for clinical trials of investigational medicinal products. It comprises of a series of lectures covering many aspects of GCP.	This is an interactive workshop for staff who are experienced in the field of clinical research and have a need to address critical issues that threaten the effectiveness of their role and their research programmes.	Aimed at developing a strategy for efficiently managing the informed consent process in an ethical and legal framework. Delegates will be given guidance on understanding the roles and responsibilities of the clinical research team throughout the consent process.	For clinical researchers who are new to the role of Principal Investigator and for researchers who expect to take on the role in the near future. It has been specifically designed to impart the regulatory requirements and GCP guidelines of the role.	Designed for clinical researchers involved in document collection and review through management of the TMF and ISF. It will allow delegates to develop greater awareness of the scope and variety of essential documents.

For information and bookings of Noclor courses, visit www.noclor.nhs.uk to download your booking form. If there is a training subject that your research staff would benefit from that we do not currently offer, please do get in touch with us at: esther.tubone@nhs.net

Finding research funding

It is possible to apply for funding from the following organisations. This is by no means an exhaustive list and deadlines have not been included. Refer directly to the organisations website for application deadlines.

National Institute of Health Research:

<http://www.nihr.ac.uk>

Medical Research Council:

<https://www.mrc.ac.uk>

Wellcome Trust:

<http://www.wellcome.ac.uk>

Cancer Research UK:

<https://www.cancerresearchuk.org>

Diabetes UK <http://www.diabetes.org.uk>

Health Foundation:

<http://www.health.org.uk>

King's Fund: <http://www.kingsfund.org.uk>

The Association of Medical Research Charities: <http://www.amrc.org.uk>

More general funding sources can be found at: <http://www.rdlearning.org.uk>

Please note that for assistance from the finance team, the researcher must contact Noclor within the timeframe given below:

Programme Grants

6 weeks prior to submission deadline.

Research for Patient Benefits Grants

4 weeks prior to submission deadline.

Programme Development Grants

2 weeks prior to submission deadline.

NIHR HTA Grants

4 weeks prior to submission deadline.

Research Council Grants

(MRC, Economic & Social Research Council)

3 weeks prior to submission deadline.

Contact the Noclor finance team at: finance.noclor@nhs.net



PUBLIC HEALTH STUDY PUTS SPOTLIGHT ON RESEARCH

A new study for the Academy of Medical Sciences has highlighted the vital role of research in strategies to improve the health of the public by 2040.

The report explores how to organise the research environment to generate and translate the evidence needed to underpin such strategies as the UK population faces a wide range of complex health challenges and opportunities over the next generation.

Recommendations from the working group – led by Dame Anne Johnson, professor of infectious disease epidemiology at UCL – include developing Health of the Public policy fellowships in government departments to build relationships and long-term networks between researchers and policymakers.

Making research everybody's business



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 twitter.com/NoclorResearch

Editorial content: **Katie Shimmon**

This paper is Forest Stewardship Council certified

Projects currently recruiting

● **PROMISE:** This study, an international first, aims to evaluate the feasibility of offering women over 18 the opportunity to find out about their risk of developing ovarian cancer.

Women are invited to participate by their GP practice, and the study team hopes to recruit 100 patients initially.

The project, funded by The Eve Appeal charity and Cancer Research UK, is led by Dr Ranjit Manchanda, of Queen Mary University, London.

● **RADAR:** This UCL-led trial will compare a gradual strategy of antipsychotic reduction and possible discontinuation with maintenance (continuous) treatment in people with schizophrenia or who have recurrent psychotic episodes.

Treating clinicians will also be given guidance on monitoring and treating symptoms and early relapse.

For information on Noclor support:
primarycare.noclor@nhs.net