

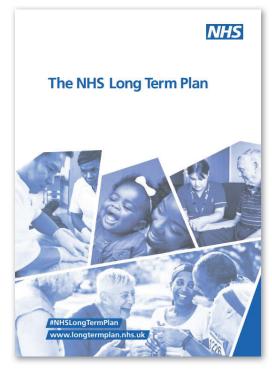
Autumn 2019 Edition No. 6

PARTICIPATE

Primary Care Networks (PCNs)

One of the objectives in the NHS Long Term Plan is to increase the number of patients registering to participate in research across the NHS to one million by 2023/24. It states that research is essential to improving patient wellbeing, and emphasises how research engagement will drive quality improvement, professional development and also generate income for the practice.

The Clinical Research Network (CRN) in the West Midlands provides a well-established infrastructure for supporting the delivery of research within Primary Care across the region, with an excellent track record for facilitating GP practices to participate in research. Over the last ten years we have



developed close working relationships with a considerable number of practices, and, with the recent introduction of PCNs, we are keen to both maintain existing relationships and also to embrace the opportunities presented by this new model for widening participation in research. The CRN is well placed to assist PCNs to develop a research strategy for GP practices and, in the longer term, to embed research in everyday practice which will both benefit patient care, and provide a robust income stream.

If you would like further information or would welcome an informal discussion, please contact either sue.elwell@nihr.ac.uk, Research Manager, or david.shukla@nihr.ac.uk, Clinical Research Specialty Lead for Primary Care.

In this edition we feature articles on:

- The ATTACK Trial, looking at whether the addition of low-dose aspirin to usual care reduces the risk of major vascular events in people with chronic kidney disease who do not have pre-existing cardiovascular disease, see page 2.
- IQVIA MRES (Medical Research Extraction Scheme) which specialises in clinical research, clinical trials and providing analytical solutions to healthcare and life sciences organisations. In the UK, they have collected and supported the research use of non-identified patient data for over 20 years, see page 4.

If you would like to contribute to Participate or for further information, please contact Jenny Oskiera, email jenny.oskiera@nihr.ac.uk

- Study SupportBack2
- Study Increasing Physical Activity in Older People with Joint Pain
- Patient Research
 Ambassador

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Supporting Self-Management of Low Back Pain

SupportBack 2

Low back pain (LBP) is one of the most common and costly problems seen in GP surgeries. Internet interventions may provide a new and efficient way of supporting and encouraging patients to become more active in selfmanagement of LBP.

The aim of this study is to determine if an internet intervention called SupportBack, provided both with and without guidance from a physiotherapist over the telephone, is effective in reducing LBP-related disability when compared to usual primary care alone.

806 Primary Care patients with current LBP will be recruited through their GP practices for a Randomised Controlled Trial comparing three groups:

- 1. Usual care
- 2. Usual care + internet intervention
- 3. Usual care + internet intervention + telephone Physiotherapist support

SupportBack provides advice and reassurance, and encourages physical activity over a six-week period. Tailored online materials support gradual goal setting, facilitate monitoring of back-related activities and provide personalised feedback. Telephone physiotherapist support will address concerns, provide reassurance and encourage uptake and compliance with activity goals.

Participants will be followed up at six weeks, three, six and 12 months. Questionnaires will explore how LBP is affecting their daily activities, their level of pain intensity and other LBP-related issues. A GP medical records review will be performed at 12 months which will record health care service use. LBP related costs will be calculated. In-depth qualitative interviews will be conducted with up to 30 trial participants across the three groups to explore their experiences of SupportBack and the care they have received over the trial period.

If you would like further information, please contact your local research facilitator, details on back page

Knowledge, Attitudes and Practice of GPs and Practice Nurses in the West Midlands Regarding Female Genital Mutilation



Female Genital Mutilation and Cutting: (FGM/C West Midlands)

We are inviting GPs and practice nurses in the West Midlands to take part in the FGM/C West Midlands study, run by the Research Institute for Primary Care and Health Sciences, Keele University in collaboration with Clinical Research Network West Midlands.

In brief, being part of this study will involve completing a **very short** online survey related to your knowledge, attitudes and practice regarding FGM/C.

You can access the survey and participant information sheet, explaining the study in more detail and how you can take part, via this link: https://form.jotformeu.com/90553645158361

** The survey will take no more than five minutes to complete **

Thank you for considering taking part in the FGM/C West Midlands study.

Recruitment status: 1 September - 30 November 2019

Sponsor: Keele University

Funder: National Institute for Health Research (NIHR) Research Professorship



If you would like to know more about this study, or have any questions and wish to speak to the researcher(s), please contact Dr Tom Shepherd via t.a.shepherd1@keele.ac.uk or 01782 734824

ATTACK (Aspirin To Target Arterial Events In Chronic Kidney Disease)



ATTACK is a pragmatic multicentre open-label randomised controlled trial to determine whether the addition of low-dose aspirin to usual care reduces the risk of major vascular events in people with chronic kidney disease who do not have pre-existing cardiovascular disease. This is a very simple study, with a very low workload for participating practices.

This study, run by the same researchers as those managing the HEAT, FAST GOUT and ALL HEART Primary Care studies, is running across the West Midlands, with over 130 patients recruited to date. Participating practices would receive service support costs to cover their time to help with this important study, and support would be provided.

Would your practice be interested in helping us with this national study?

The Trial Manager is Jen Dumbleton, email: jennifer.dumbleton@ nottingham.ac.uk, phone: 0115 823 1053

Increasing Physical activity in Older People with joint Pain



Study background

Physical activity levels in older people with chronic musculoskeletal pain are low. Lower activity levels are associated with increased pain and disability. Walking is a straightforward way of increasing physical activity, which is accessible, inexpensive and low impact.

iPOPP is a three-arm randomised controlled trial which aims to test whether a brief behavioural intervention (iPOPP) increases average step count compared to usual primary care or receiving a pedometer and activity diary in the post in adults aged 65 years and over with chronic musculoskeletal pain.

We are looking for approximately 57 practices to take part in the study. We need a practice population size of 400,000 within the West Midlands in order to recruit a total of 1085 patients. Each practice will provide approximately 20 participants.

What will be asked of practices?

- Allow access to CRN staff to conduct a practice list search for potentially eligible patients
- GP to screen patient list for ineligible patients, CRN to complete Docmail invites for suitable patients
- Provide clinic time and space for a Health Care Assistant (HCA) to deliver the walking intervention to patients (n=6, based on a list size of 7,000), which includes 2 x 30 minute appointments, the latter of which may be a telephone consultation

Option 1 - Practice Health Care Assistant

Allow the practice HCA to attend two full days training at Keele University. Practices will be paid for practice HCA consultation time and for allowing the HCA to attend the training. If you are signed up to the CRN RSI scheme, this study will be paid at Grade Two, £700.

Option 2 - HCA provided by the study team

If you are signed up to the CRN RSI Scheme, this study will be paid at Grade One, £300.

What are the benefits of participating?

For patients this trial offers the opportunity to get involved in research and potentially receive a programme of support to increase physical activity levels. For practices this trial offers the opportunity to participate in research which can be reported as part of appraisal and revalidation and give their patients the chance to be involved in research.





Participant identification began in spring 2019. If your practice is interested in taking part, or would like further information, please contact Lucy Andrew, CRN Research Facilitator, details on back page, or Kate Fisher, iPOPP Trial Manager on 01782 734882 or k.l.fisher@keele.ac.uk

Improving Antibiotic Prescribing for Children with Ear Discharge

We are recruiting!

Researchers at the Universities of Bristol and Southampton are looking for GPs and nurse practitioners nationwide to help recruit 399 children to a study comparing antibiotic treatments for Acute Otitis Media with discharge (AOMd).

Read all about it...

It is believed that nearly all children with AOM or AOMd in the UK are treated with oral antibiotics. It may be that alternative treatments such as an antibiotic eardrop or delayed oral antibiotics could be at least as effective as immediate oral antibiotics for children with AOMd. With your help we will recruit children aged ≥12 months to <16 years over a recruitment period of 22 months (starting in July 2019). To help you recruit, we are using a cutting-edge, secure electronic platform that automatically integrates with GP electronic medical records to help you through the process and avoid duplicate data entry.

We need to recruit 72 children by the end of this year. Please get in contact if you think your practice would be interested in supporting the first national trial of its kind, email rest-study@bristol.ac.uk

The National Centre for Mental Health



Aims: To improve diagnosis, treatment and support for the millions of people affected by mental ill-health every year; tackle stigma.

How is this done? Engagement with services and their users, the third sector and the wider public to increase understanding of mental illness, and by supporting and undertaking mental health research.

How can you help? Mental health problems can affect anyone regardless of age, gender, race or social background. But together we can make a difference.

Current focus: Bipolar Disorder; Schizophrenia and Psychosis; Postpartum Psychosis; PTSD; Schizoaffective Disorder

What is involved?

- 30- 60 minute assessment at the participant's home or a nearby clinic
- Personal information and background, family history, physical and mental health diagnoses, medication history and lifestyle questions
- DNA sample- blood/saliva
- Questionnaire left with participant

Enhancing The Health Of NHS Staff

Absenteeism and presenteeism costs the NHS approximately £2.4 billion per year and is associated with worse patient outcomes. The main causes of NHS staff absenteeism are musculoskeletal complaints and mental ill-health. Lifestyle factors such as smoking, obesity and low levels of exercise leading to poor cardiovascular health are also important factors.

eTHOS is a multicentre, randomised controlled pilot trial of an employee health screening clinic for NHS staff. The aim of this NIHR funded trial is to evaluate the effectiveness and cost-effectiveness of a complex intervention in reducing absenteeism and presenteeism in NHS staff, comparing a hospital-based staff health screening and referral clinic with usual care.

This pilot trial is due to start in autumn 2019. We aim to recruit 480 participants across 3 NHS Hospital Trusts in the West Midlands and Herefordshire.

What will it involve for participants?

- Participants will provide written consent and complete on-line questionnaires at baseline, 26 and 52 weeks
- Participants randomised to either
 - a. attend the staff health clinic and receive assessment for their musculoskeletal, mental and cardiovascular health (or lifestyle advice for those <40 years)
 - b. usual care they would not attend the staff health clinic but would see their GP if they had any health concerns

What will it involve for GP practices?

- We will inform you if any of your patients consent to participate
- We will notify you of any test results and potential actions that you may wish to consider
- We may invite you to tell us about your experience of receiving information from the trial and the acceptability of the process

If you would like to find out more please contact the trial team on 0121 414 8137 or ethos@trials.bham.ac.uk

IQVIA MRES(Medical Research Extraction Scheme)

The Clinical Research Network West Midlands is pleased to announce that we are working with IQVIA to support practices to sign up to the Medical Research Extraction Scheme.

About

IQVIA specialises in clinical research, clinical trials and analytical solutions to healthcare and life sciences organisations. In the UK, they have collected and supported the research use of non-identified patient data for over 20 years. They have partnered with EMIS Health to offer your practice the opportunity to contribute non-identified data to the research and patient insights programme.

How to join

Joining is a one-time, straightforward process, after which non-identified data is regularly collected automatically from EMIS Web with no impact on day-to day activities.

Benefits for your practice

Your practice would benefit from a quarterly payment of six pence per patient (based on NHS list size).

Data

The data available for research will not include any identifying information on healthcare professionals or patients. IQVIA uses a wide variety of privacy-enhancing technologies and safeguards to protect individual privacy while providing insights that can help drive health policy changes leading to improved outcomes for patients. For more details, visit:

https://www.iqvia.com/locations/ uk-and-ireland/medical-research-data

These insights include approved scientific research studies for many uses such as epidemiology, drug safety and risk management, public health research, drug utilisation studies, outcomes research and health

IMS Health & Quintiles are now



economics research. You can access the complete IQVIA bibliography at http://www.rwebibliography.com

Approvals

The use of IQVIA™ Medical Research Data extracted from the GP software systems for the purpose of medical research and of supplying the data to external researchers for scientifically approved studies under Data Sharing Agreements has been approved by the NHS Health Research Authority (NHS Research Ethics Committee ref 18/LO/0441).

If you want to know more about the IQVIA data collection programme and take part in the journey to improve patient outcomes, please contact CRN MRES Lead, Saif Uddin, email: saif.uddin@nihr.ac.uk

Alzheimer's Society Annual Conference 2019

Promoting Join Dementia Research (JDR) in Primary Care

by Gerri Mulcahy

I was proud to attend the Alzheimer's Society Annual Conference at the Oval Cricket Ground in London on 21 May 2019 to



display a poster demonstrating the hard work our Primary Care JDR Working Group and colleagues have been doing around the West Midlands over the last 12 months. The event was attended by leaders in health, social care, government, policy and research together with members of the research community and Alzheimer's Society volunteers.



Richard Madeley (TV presenter, pictured) opened the conference talking about his personal experiences of dementia and how it affected his family. There were various speakers with talks during the day including:

"Breaking new knowledge in dementia; towards new diagnosis and treatment",

and

"From proving to improving: the involvement of people affected by dementia in research".

There were many opportunities or delegates to network and view posters and it was good to see all the hard work that is being done for dementia sufferers and their families. Sanctuary Housing were very interested and commented that they would like to collaborate with us in the future.

In an increasingly competitive research environment, securing funding to conduct health and social care research can be difficult and time consuming. The National Institute for Health Research



(NIHR) Research Design Service provides expert advice and support to researchers developing research funding applications.

How we can help

We could help your team with:

- designing a research study
- research methods (qualitative and quantitative)
- identifying suitable sources of funding
- involving patients and public in research design
- identifying potential academic, clinical and lay collaborators
- identifying and refining the research question
- medical statistics
- health economics
- advice on common pitfalls
- interpreting feedback from funding panels

Who we can help

We can help you if you are:

- developing grant applications for applied health or social care research
- applying for personal fellowships
- writing applications to national, open, peer-reviewed funding streams

We support a broad range of people, including doctors, nurses and allied health professionals; patients and service users; academics and NHS and social care managers. Our priority is to support applications to NIHR research funding streams. We also support applications to Research Councils and other open, national, peer-reviewed funding programmes.

Why choose us

Expertise: Our research advisers offer a unique breadth of expertise and a proven track record in improving research applications.

Collaboration: We can help you to identify possible gaps in your research team and collaborators who can add value to your research, including health and social care clinicians, policy makers, academic researchers and patients and the public.

Tailored support: We can offer support tailored to the needs of your research team. Advice is available at face-to-face meetings, by telephone or email, at research clinics or as feedback from panel review meetings.

If you require further information please visit our website: https://www.rds-wm.nihr.ac.uk or contact us direct:

Birmingham Hub (and general enquiries):

Karen Biddle, Administrator, RDS WM Birmingham Hub Email: rds@contacts.bham.ac.uk Tel: 0121 414 8533

Keele Hub: Valerie Davies, Administrator, RDS WM Keele Hub Email: primarycare.rds@keele.ac.uk Tel: 01782 732929

Warwick Hub: Stephanie Smart, Administrator, RDS WM Warwick Hub Email: rds@warwick.ac.uk Tel: 02476 150493

Building a partnership with the East Staffs Group Network

By Gerri Mulcahy

I started working as a Primary Care Research Facilitator in January 2017; one of my first objectives was to engage with the East Staffordshire CCG practices as initially there was only a handful of practices doing research in that area. Two years later, nearly 90% of the 18 practices are active or ready to commence research. Of the remaining practices we are looking at ways in which to overcome IT/time constraints.

Communication is key to developing successful relationships with each of the practices; visiting the practices and meeting them face to face is beneficial, and helps build up trust as well as giving the practices a main point of contact for all research activities. This was fundamental to the group's engagement with research. It takes continuous liaising with the practices to improve communication. When I circulate a study, I ensure this is followed up with phone calls/further emails to ascertain if there is any interest.

Progress meeting with Richard Hibell, Gerri Mulcahy, Debbie Melling, Joanne Beanland

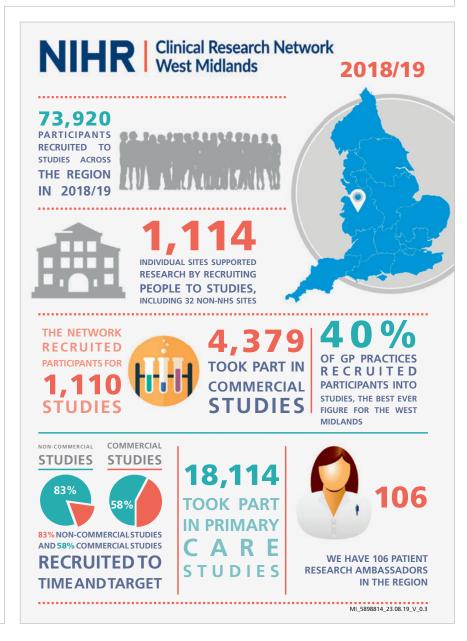
This approach has definitely led to better practice engagement. It was useful to have studies to offer that were of key interest to GPs, and that helped with treatment of key conditions. Eight of the practices participated in I-WOTCH and CHESS, some also participated in TAPS, ACDC, HILL and TUDOR. By engaging in these studies practices gain an idea of how research works and how we can support successful delivery.

The NCMH study is of key interest to practices by raising the profile of mental health in primary care. Richard Hibell and

Sorela Mazilu-Wood, Research Nurses, attended practice meetings which were instrumental in developing the clinical aspect of nurses working with the practices and gave more support, thereby raising our profile. It has been great to hear such positive feedback from practices of their experiences of working with them. We are looking forward to rolling out NCMH to the whole group.

Via Howbeck Healthcare, which formed the East Staffordshire Federation, the practices applied for the pilot group scheme that allowed for improved collaborative

working and a joining together to embed research in everyday practice. Both Peel Croft Surgery and Mill View Surgery have come on board as the hubs for the group and we are working together to take this forward. It has been a positive and rewarding experience working with Debbie Melling and Joanne Beanland, and is refreshing to see their enthusiasm in working with us to give their patients the best opportunity to be involved in research. This piece of work leads onto our collaboration with all primary care networks within the West Midlands.....watch this space.



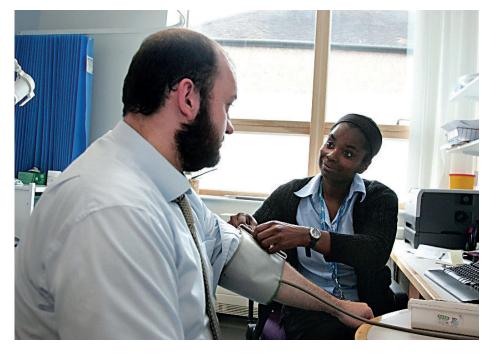
An Investigation of Skill Mix in Primary Care

Many general practices are finding it difficult to recruit additional doctors (GPs) to deal with their increasing workload. Practices are therefore employing a wider range of types of health care professionals in a change that is generally referred to as 'skill mix' and which aims to ease pressure on GP appointments.

Patients can consult directly with non-GP practitioners; nurses who prescribe medicines, pharmacists who advise about medications; or a newer type of practitioner called 'physician associate' for help with a diagnosis and advice about treatment.

However, there is limited information about how patients may experience care differently when non-GP practitioners are introduced or how this change affects the quality and costs of care. More information is also needed about how practitioners from different backgrounds work together and whether supervision or duplication of work may limit the extent to which their employment reduces GP workloads.

To find out about this, the 'big picture' of what happens when GP practices employ new types of practitioners will



be examined. National data will advise how widely the change in skill mix is happening in GP practices; this change can be investigated as to its effect on what happens, e.g. how many patients are referred to hospital specialists or given prescriptions.

More information will be obtained by talking to practice staff about how practitioners work together, asking patients whether they like these new roles and if they know how to get most benefit from them. GPs and Practice Managers will be asked about why they choose to employ different types of practitioner and what they expect them to do.

The combination of these research activities will assist to identify the consequences of changes in skill mix, and help to identify how practices and patients can benefit most.

Farewell to Mark Porcheret, CRN West Midlands Clinical Research Lead

It is with mixed emotions that we announce Mark Porcheret's retirement, sad because we don't want him to go, happy that he will be getting the time to spend with his two favourite things - his family and his garden.

In 2009 Mark joined the Clinical Research Network as GP Director of the Primary Care Research Network, West Midlands North, which was the beginning of his contribution to the NIHR in improving the health and wealth of the nation through research.

Mark moved on to become Clinical Director of PCRN Central England in

2011 and more recently Clinical Research Lead for Primary Care and Deputy Clinical Director for the CRN West Midlands. Mark has shown ongoing initiative, leadership and dedication and has been an exceptional ambassador, exerting a positive influence over internal and external stakeholders, earning the greatest of respect of his peers. He has become a significant role model in the field of Primary Care both nationally and locally with his outstanding vision and his dedication to the service.

We all wish him the very best for his retirement and for the future.



Developing and Testing a Patient Explanation Package for OsteoArthritis (PEP-OA)

PEP-OA is a study that will develop and test the way doctors, nurses and other healthcare professionals explain osteoarthritis when they are talking to patients.

A Patient Explanation Package for OsteoArthritis (PEP-OA) will be developed.

This will contain materials for patients and will be supported by a package of information for healthcare professionals to help them:

- Use the explanation
- Understand the importance of getting their explanations right

PEP-OA and the supporting package will be developed by:

- 1. Developing and ranking the importance of osteoarthritis explanation statements to support patients in self-managing their condition
- 2. Testing explanation statements to establish the impact of the statements ranked as being important
- 3. Designing written and cartoon versions of a core explanation (relevant to all patients with osteoarthritis) and additional written statements (to tailor the core information to individual patients).
- 4. Testing these with patients with osteoarthritis, lay people without osteoarthritis and healthcare professionals who diagnose osteoarthritis. Once tested, the feedback and learning will allow us to finalise PEP-OA

Practice Praise

Our thanks go to:

- Albrighton Medical Practice
- Cleobury Mortimer Medical Centre
- Trentham Mews Medical Centre

For carrying out at least two searches and mail outs to patients, and showing excellent commitment to recruiting to this study.







Patient Explanation Package for OsteoArthritis

CRN West Midlands are looking for four GP practices to take part in part two of the study "Testing the Impact of the Important Explanation Statements" which will be done as a conjoint analysis.

Practice activity:

- Practice staff to search medical records of participating practices (with the support of CRN Research Facilitator)
- GP screen list
- Practice staff to process mail out via Docmail to a random sample of 375 patients - invitation letter, Information Sheet and Questionnaire (with the support of CRN Research Facilitator)
- Provide study team of anonymous key demographics (Age and Gender) for all patients mailed (with the support of CRN Research Facilitator)
- Practice staff to process reminder one mail out to non-responders - reminder letter, Information Sheet and Questionnaire (two weeks after mail out) (with the support of CRN Research Facilitator)
- Practice staff to process reminder two mail out to non-responders - reminder letter, Information Sheet and Questionnaire (four weeks after mail out) (with the support of CRN Research Facilitator)

RSI Scheme payment: £300 (Grade One study) dependent on completion of all listed study related tasks

Study Support costs: Paid for practice staff time in screening and mailing

Recruitment status: October 2019 - January 2020

Chief Investigator: Dr Claire Jinks

Sponsor: Keele University

Funder: National Institute for Health Research

(Research for Patient Benefit)



For further information, please contact your local research facilitator, details on back page.

Fundamentals of Clinical Research Delivery

By Jon Davies, Research Nurse, CRN West Midlands (CRN WM) and Good Clinical Practice (GCP) Facilitator

Last year the National Institute of Health Research (NIHR) released a new training course called "Fundamentals of Clinical Research Delivery", which members of the CRN Primary Care GCP Facilitator Working Group have recently amended to make more relevant to Primary Care.

Fundamentals training is intended for members of staff who will not have freedom to act in a research study.

In other words, it is for staff who will only be peripherally involved or occasionally assisting in a study, e.g. Health Care Assistants or Practice Nurses (PNs) who are performing routine clinical procedures for research purposes and, as such, do not need full study or GCP training. Primary Care Fundamentals is an approximately two-hour course delivered in-house, and certificates are provided.

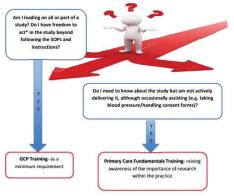
Fundamentals does not replace full GCP training for staff who will have freedom to act in a research study, e.g. lead study GPs or PNs, and this will depend on the type of study as directed by the study Sponsor.

Fundamentals has further been amended in primary care as a research awareness course to make it more relevant to non-clinical practice staff who work in research active practices, e.g. receptionists, administrators etc. This course takes one hour, is delivered in-house, and certificates are provided.

The Primary Care research courses provided by the CRN WM are as follows:

- Full Primary Care GCP training (either in-house or online)
- GCP Refresher (in-house or online)
- NIHR Fundamentals for Primary Care training (in-house only)
- Primary Care Research Awareness Training (in-house only)
- Informed Consent training (in-house)

GCP Training vs Fundamentals of Clinical Research Delivery: what training do I need?



"Freedom to Act" is anyone who is expected to use their more detailed knowledge of the study processes, GCP and

Further Information:

GCP Training:https://www.nihr.ac.uk/our-faculty/clinical-research-staff/learning-and-development/national-directory/good-clinical-practice/Decision Aid: https://sites.goodle.com/anihr.ac.uk/dandtda/Queries: Email: Training.crnwestmidlands@nihr.ac.uk

If you wish to find out more please ask your local research facilitator or research nurse who should be able to assist you, details on back page, contact the CRN Workforce Development team or Jon Davies direct on

jonathan.davies@nihr.ac.uk

Join Dementia Research (JDR) Event at Holmcroft Library



By Geoff Robson, Patient Research Ambassador

On 5 June, a JDR event was held at the Holmcroft Library in Stafford. In preparation, posters were displayed at the library, in

local retail outlets and at two local GP surgeries among others, and a radio interview was held with Stafford FM. The event was led by Jackie Smart (Research Facilitator) assisted by Geoff Robson (Patient Research Ambassador – pictured).

Although they talked to a few people in the Library, and gave out forms to them, the overall response was disappointing and frustrating with no one attending who had seen the posters or heard the interview. It remains a challenge to raise public perception of the JDR initiative, even though this forms part of the government's 2020 Dementia Strategy.



Welcome to John Bentley, Patient Research Ambassador

John writes: "I have been working with the Clinical Research Network for a couple of months. I chose to get involved because I am a firm believer in the NHS, where I worked for 37 years. In addition, I had experience as a carer for my mother in law until her death, and latterly as a patient.



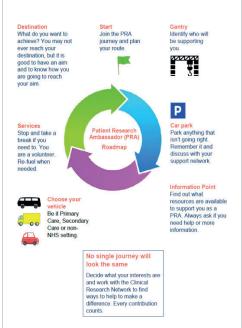
"God bless the NHS: it certainly came to my aid when I tried to kick heaven's door in. Following a brain haemorrhage and a stroke, I am now partially sighted, but my life was saved by the interventions devised through research and development. I am not blind to the failings of the system, or delivery, and any opportunity I can see to make a difference by improving care for others is well worth grasping. I am confident that there will be opportunities to have my say, share my experience, and use my brain.

"NHS and social care staff do a sterling job under increasingly difficult circumstances. Anything we can do to encourage, develop creative solutions, and share good practice must be of benefit to all."

Patient Research Ambassadors (PRAs)

Why it is vital to have more PRA representation in Primary Care:

- To engage with GP practices
- To raise awareness of health research in general practice
- To engage with marginalised groups
- To engage with study teams
- To co-produce research
- To identify areas for research that are relevant and important to patients
- To increase visibility of research within general practice
- To reduce health inequalities through innovation and opportunity to be involved



Are you a patient who is interested in being more involved? Are you a health professional who has dealt with a motived and engaged patient who might be interested in helping the CRN with their patient engagement?

For further information, please contact Eleanor Hoverd, research nurse, email: eleanor,hoverd@nihr.ac.uk

JDR at Waverley House

By Claire Brown, CRN Research Nurse

As part of the CRN's ongoing mission to promote Join Dementia Research (JDR) in the West Midlands, we recently started a new collaboration with Waverley House, a care home in Leominster owned by Shaw

Healthcare, which provides specialist nursing care for people with dementia and residential care for over 65s. The Deputy Manager, Samantha Turner, is passionate about improving the lives of people with dementia and is keen to support JDR promotion in Herefordshire.

We discussed a range of ideas about how Waverley could help to publicise JDR and decided firstly to motivate staff with the knowledge needed to confidently signpost service users to JDR. Samantha and I showed the JDR promotional

video and promoted the NIHR JDR learning tool at their monthly staff team meeting, discussing the importance of equal access for all to participation in dementia research and the role they can play.



Staff at Waverley House



To promote JDR to residents, relatives and visitors to the home, Samantha has set up a display in the main entrance, with posters, leaflets and registration forms and kiosk, allowing people passing through to register their interest. Additionally, the promotional video is on their welcome area screen, and social media platforms. It is planned to discuss JDR at the next residents' meeting and at relatives' meetings.

Looking to the Future

The response to JDR from Samantha and her team has been overwhelmingly positive, and has opened up many further opportunities; they have also signed up to Enabling Research in Care Homes and are keen to participate in future research. We await registration figures, but are hoping to see a steady rise in signups as the promotion continues.

Moving forward, we are in discussions with Shaw
Healthcare, with over 90 care homes, about how they can
help with promoting JDR nationally. They have already begun
distributing the JDR videos, and with Waverley leading by as

distributing the JDR videos, and with Waverley leading by example, it is hoped that other homes within the organisation will soon follow suit.

Samantha says, "Claire and I trained together many years ago and went off on different career paths, but I always knew we would join together again, and what better way than through this exciting collaboration. I am touched that Claire thought to contact us at The Waverley and I am so glad she did. It has sparked a new area of interest for me personally and professionally, and I am now in the process of becoming a Join Dementia Research Professional Champion. Here at The Waverley, we provide person-centred nursing, residential and day care for those suffering with Dementia, and therefore really understand and appreciate how important dementia research is in order to increase knowledge and improve future care and treatment.

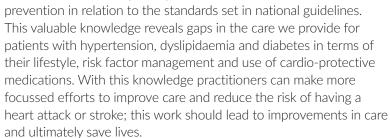
"There are many ways that I feel I/we can help to promote JDR at the Waverley. We have many external visitors to the home, including Healthcare Professionals from different organisations, some who have already taken an interest and asked for Claire's details and they feel they can help. I am more than happy to help promote the service not only to our residents, staff and visitors, but also more widely through SHAW Healthcare, and within the local community that both Claire and I grew up in."

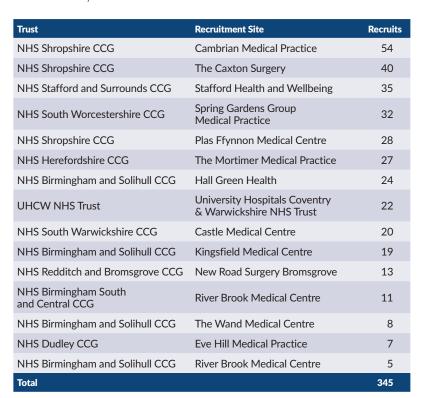
Euroaspire V/Aspire-3-Prevent Survey

The Euroaspire V/Aspire-3-Prevent Survey of Cardiovascular Disease Prevention and Diabetes has recruited a total of 558 participants. Data was collected in the West Midlands, East Midlands, Yorkshire, London, Kent and Sussex, South West Peninsula and Oxfordshire.

Congratulations to all involved, and special thanks to CRN West Midlands, with a total of 345 recruited.

In undertaking this research we describe the status of primary





Our congratulations and thanks go to all the practices involved for their hard work on recruitment, and to everyone in the CRN who has supported them.

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Aim

The relationship between outcomes and time after diagnosis for patients with non-valvular atrial fibrillation (NVAF) is poorly defined, especially beyond the first year.

Methods and results

GARFIELD-AF is an ongoing, global observational study of adults with newly diagnosed NVAF. Two-year outcomes of 17,162 patients prospectively enrolled in GARFIELD-AF were analysed in light of baseline characteristics, risk profiles for stroke/systemic embolism (SE), and antithrombotic therapy. The mean (standard deviation) age was 69.8 (11.4) years, 43.8% were women, and the mean CHA2DS2-VASc score was 3.3 (1.6); 60.8% of patients were prescribed anticoagulant therapy with/without antiplatelet (AP) therapy, 27.4% AP monotherapy, and 11.8% no antithrombotic therapy. At two-year follow-up, all-cause mortality, stroke/SE, and major bleeding had occurred at a rate (95% confidence interval) of 3.83 (3.62; 4.05), 1.25 (1.13; 1.38), and 0.70 (0.62; 0.81) per 100 person-years, respectively. Rates for all three major events were highest during the first four months. Congestive heart failure, acute coronary syndromes, sudden/unwitnessed death. malignancy, respiratory failure, and infection/ sepsis accounted for 65% of all known causes of death and strokes for <10%. Anticoagulant treatment was associated with a 35% lower risk of death.

Conclusion

The most frequent of the three major outcome measures was death, whose most common causes are not known to be significantly influenced by anticoagulation. This suggests that a more comprehensive approach to the management of NVAF may be needed to improve outcome. This could include, in addition to anticoagulation, interventions targeting modifiable, cause-specific risk factors for death.

Publication: https://academic.oup.com/eurheartj/article/37/38/2882/2336152?searchresult=1

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Changes to the Research Sites Initiative Scheme



After running its current format for several years, the Research Sites Initiative (RSI) scheme is now being reviewed. With the changing primary care landscape, with practices merging and new Primary Care Networks emerging, we need to ensure that any future scheme is fit for purpose and can work with all GP practices, whatever the list size.

The requirements for signing up to the scheme have changed with the introduction of the new guidelines on Good Clinical Practice training and the ongoing review of the Research Ready accreditation scheme. With these changes in mind the CRN is looking to refine the RSI scheme payments to put the emphasis on taking part in studies rather than the other basic requirements.

Our proposal is to make the initial payment on a per patient accessed basis, linked to list size, with an additional per study payment that continues to reflect the difficulty of the study and the practice work involved, but at a higher rate than currently.

Overall, we expect practices to see a similar level of funding for a similar level of activity.

In January 2020, we will be inviting practices to be part of the RSI scheme; for many practices research is part of core business and they sign up to the scheme each year, but we are always keen to hear from new practices who would like to learn more about research, the benefits to their patients and the practice and more information about the initiative scheme we run.