

# PARTICIPATE

## Patients' Experience of Research: what can research do for you?

Patient and Public Involvement and Engagement (PPIE) is key to achieving ethically sound research that is relevant to those most likely to benefit from it. It is practical commonsense to involve the public not only in the design of research, as this increases its viability and promotes willingness to participate in studies, but also in the interpretation of data and the dissemination of findings.

Early stage PPIE input into research enables smoother running of projects by ensuring that contact methods and times are appropriate and sensitive to any specific cultural community requirements. It also helps to ensure appropriate wording for research materials, such as consent forms, and questionnaires. For PPIE to achieve its full potential, it is important that it is inclusive and allows a diverse range of individuals to contribute. This may mean using a range of methods – for example, meetings in different localities or with faith communities, online surveys, contact with voluntary groups etc.

Within the West Midlands, the PPIE team of the CRN is looking for volunteers who might be interested in becoming Patient Research Ambassadors (PRAs) to promote health research from a patient point of view. If you are interested, or know of someone who might be, please contact Moe Shaikh, CRN WM PPIE Cross Cutting Theme Lead on 024 76430165 or email [mohammed.shaikh@nhr.ac.uk](mailto:mohammed.shaikh@nhr.ac.uk)



The Patient Research Experience Survey 2016-17 was carried out nationally across England, following a pilot in 2015 and showed a high level of satisfaction among those who participated in research. The results show how much patients valued research and the benefits that are gained.

### In this edition we feature articles on:

- I-WOTCH: a multicomponent self-management intervention targeting withdrawal of strong opioids for people living with persistent pain (page 2)
- ARCHIE: a double-blind randomised placebo-controlled trial which aims to determine the effectiveness of giving antibiotic co-amoxiclav to 'at risk' children within five days of them becoming ill with flu or influenza-like illness (page 3)

If you would like to contribute to Participate or for further information, please contact Jenny Oskiera, email: [j.oskiera@warwick.ac.uk](mailto:j.oskiera@warwick.ac.uk) or [jenny.oskiera@nhr.ac.uk](mailto:jenny.oskiera@nhr.ac.uk)

- Study – CHES
- CRN – update from Pauline Boyle, Chief Operating Officer
- PPIE – Patient Research Ambassadors Needed
- Events – RCGP Midland Faculty Symposium 2018

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# West Midland Wide Studies



## i-WOTCH

## IMPROVING THE WELLBEING OF PEOPLE WITH OPIOID TREATED CHRONIC PAIN

### Seeking GP practices to host i-WOTCH study on opioid withdrawal for chronic pain

We are currently recruiting GP practices across the whole Midlands region to take part in the I-WOTCH study. We are a multi-centre, randomised controlled trial aiming to test the effectiveness and cost effectiveness of a multicomponent self-management intervention targeting withdrawal of strong opioids for people living with persistent pain in comparison to best usual care. The chief investigator for the study is Dr Harbinder Sandhu at the Clinical Trials Unit, University of Warwick.

We plan to recruit 468 participants from around 100 general practices, community pain/musculoskeletal services and pharmacies across three locations: the Midlands, North East England and Greater London.

The I-WOTCH intervention is targeting patients using Buprenorphine, Dipipanone, Morphine, Diamorphine, Fentanyl, Methadone, Oxycodone, Papavertum, Pentazocine, Pethidine, Tapentadol, or Tramadol for the treatment of persistent non-cancer pain. These drugs account for 95% of UK strong opioid prescribing in primary care.

#### What will it involve for participants?

All participants will be asked to:

- Provide written consent and complete postal questionnaires at baseline, four, eight and twelve months
- Complete a weekly diary booklet recording symptoms and quality of life for four months from baseline

**Funding Acknowledgement:** This project is funded by the National Institute for Health Research, Health Technology Assessment (project number 14/224/04). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HTA, NIHR, NHS or the Department of Health.

If your GP practice is interested in the study or for more information, please contact your local facilitator, please see back page.

#### Participants will be randomised to either:

- **Usual GP care plus a self-learning manual**  
Participants will receive a manual with advice about chronic pain management and potential implications and adverse effects of using opioids, and a relaxation CD plus usual GP care.
- **Usual GP care plus a support programme**  
Participants will attend a three day self-management course led by an I-WOTCH nurse and a lay facilitator held at a venue close to their practice. There will be an average of 12 people in a group. Participants will have two one to one meetings and two telephone calls with the nurse. The nurse will create an opioid tapering plan for the participant at the first meeting and then monitor and discuss their progress over the calls and final one to one meeting. Participants will receive the self-learning manual, relaxation CD, educational DVD and mindfulness CD plus their usual GP care.

#### What will it involve for GP practices?

- Identification of potential participants from computer record search
- Checking of list before mail-out
- Mail out of study invitation letters (via Docmail)
- Access to patient records at a later date for data collection of consultations, health service activity, prescriptions and NHS number

## Chronic Headache Education and Self-management Study (CHES)



A multi-centre, randomised controlled trial evaluating an education and self-management support programme for people living with chronic headaches (headache  $\geq$  15 days/month for  $\geq$  3 months). The trial is led by Professor Martin Underwood at the Clinical Trials Unit, University of Warwick.

**We are currently recruiting people aged  $\geq$ 18 years living with chronic headaches from the Midlands and North-east London.**

#### What will it involve for participants?

All participants will be asked to:

- Complete an electronic diary of headache frequency, duration and severity weekly for 6 months and monthly for a further 6 months
- Complete a telephone interview with a research nurse to classify their headache type
- Complete postal questionnaires at baseline, 4, 8 and 12 months

#### Participants will be randomised to either:

- a. A group headache education and self-management support programme.* Participants will attend a two day education and self-management course held at a venue close to their practice; followed by a one-to-one consultation and up to eight weeks of telephone support with a nurse
- b. Usual GP care plus relaxation CD.* Participants will receive standard treatment and sent a relaxation CD

#### What will it involve for GP practices?

- Identification of potential participants from computer record search
- Screening of list before mail-out
- Mail-out of study invitation letters (via Docmail)
- Access to patient records for data collection of consultations, health service activity, and medication use related to headaches at 12 months

If your practice is interested in taking part in the study or you would like any further information regarding CHES please contact your local research facilitator, details on the back page.

## ARCHIE - The early use of Anti-biotics for 'at-risk' Children with Influenza



### Study summary

Children with underlying medical conditions such as asthma, diabetes and cerebral palsy are 'at risk' of becoming more unwell from bacterial infections if they get flu. ARCHIE is a double-blind randomised placebo-controlled trial which aims to determine whether giving the antibiotic co-amoxiclav to 'at risk' children within five days of them becoming ill with flu or influenza-like illness might:

1. Help stop them from developing bacterial infections and becoming more unwell
2. Help them get better more quickly
3. Affect how well antibiotics work against similar infections in future

**Practice involvement:** We are looking for practices to

- Identify and flag potentially eligible patients via a database screen prompt
- On presentation of an eligible patient during the winter season to call the ARCHIE recruitment hotline to inform central trial office if family happy to be contacted (approx. 5-10 min call)

A CRN nurse will then attend the patient at home for consent, baseline, randomization and study medication dispensing. The CRN nurse will carry out follow up including medical notes review. The practice may be asked to give additional information if their participant has an SAE.

**Patient involvement:** In addition to the child completing a five day course of study medication a nose and throat swab will be taken. Family will be asked to complete weekly diary for a month after study entry.

**Recruitment status:** Seasonal from October to April.

**Funder:** NIHR's Programme Grants for Applied Research Programme.



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

## PACT - Testing the Delivery of the Best Asthma Treatment Based on Genetics



A study by researchers from across the UK, funded by Action Medical Research, is aiming to discover whether treating asthmatic children according to their genetic status can improve their quality of life and asthma control.

One in every 11 children in the UK has asthma. When asthma is well managed, children can lead full and active lives. Unfortunately, not all asthma is well controlled. There is evidence that the routinely used controller medication salmeterol is ineffective in 1 of 7 cases. Previous work by Professor Somnath Mukhopadhyay from Brighton and Sussex Medical School suggests that certain gene variations are linked to poor asthma control in children.

As a result, working with general practitioners, PACT is designed to assess the effectiveness of prescribing children, whose asthma is inadequately controlled, either salmeterol or montelukast according to their beta2 receptor genetic status compared to standard asthma management regimes. Participants' genotype status is established from self-administered saliva tests.

PACT is novel as no hospital visits are required with all outcome data being completed by participants online at three monthly intervals for one year. This design allows participants to complete their quality of life and asthma control questionnaires at their convenience, with associated costs reduction.

At the end of the study, all participants and GPs will receive gene test and study results.

Healthcare professionals can find out more about the study at [www.pactstudy.org.uk](http://www.pactstudy.org.uk) or by calling the Tayside Clinical Trials Unit on 01382 383932.



If your practice would like to take part, or would like further information, please get in contact with your local research facilitator, details on the back page.

## QUALITY of life, Sleep and rheumatoid ARthritis: QUASAR



The quality of life, sleep and rheumatoid arthritis, or QUASAR, has been designed by Dr John McBeth to investigate the relationships between sleep and quality of life and asks participants to wear a sleep monitor 24 hours a day for 30 days, while using a smartphone app to record daily symptoms.

Talking about the importance of the study, Dr McBeth explains:

*"There's evidence that people with rheumatoid arthritis (RA) report high levels of sleep disturbance and we don't*

*yet know why that is. What we do know is that research suggests that disturbed sleep is linked to poor health related quality of life. By focusing on the interaction between how people sleep and factors that affect our everyday lives, for example levels of pain and fatigue and our mood, it is hoped that the results of the QUASAR study will enable us to develop new, or better target existing, sleep interventions to ultimately improve the quality of life of those with rheumatoid arthritis who experience sleep disturbance."*

### Who is eligible?

- ≥18 years
- Diagnosis of RA and use of DMARDs
- Access to an Apple/Android smartphone/tablet
- No shift work

### Primary care support

QUASAR is open to new PIC sites who will be responsible for displaying posters. We would also like to chat to practices with the ability to screen GP databases to assist in the mailout of GP letters.

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



# The West Midlands Primary Care Team

## Supporting the delivery of research in the primary care setting

by Pauline Boyle, Chief Operating Officer, Clinical Research Network West Midlands.



*Over one million people have taken part in Primary Care research nationally in the past 10 years, and 175,000 of these were recruited in GP practices in the West Midlands. The contribution of these practices is significantly helping the NHS to gather evidence about new treatments and services in order to improve patient care.*

### What did we do well as a Clinical Research Network and as a Primary Care Speciality last year?

As one of 15 Local Clinical Research Networks (CRNs) in England, the CRN West Midlands has been recognised for innovation and improvements in a number of key areas. For example, our leadership and support of the Patient and Public Involvement and Engagement induction programme, our continuous improvement initiatives and success in exceeding our participant recruitment target. Primary Care is one of our 30 specialities and the primary care delivery support team contributes significantly to these areas of success. Their engagement with the GP practices and community pharmacies, and their support for the delivery of National Institute for health Research (NIHR) Portfolio studies in both the Primary and Secondary Care settings is pivotal to the increasing the opportunities for patients to take part in research across all of our specialties. Primary Care in the West Midlands recruited just short of 10,000 patients into NIHR portfolio studies last year, which was a significant contribution to both our recruitment target and future funding. Interestingly, an increasing amount of the work that they undertake supports the wider Network endeavour rather than just Primary Care and can often go unrecognised. For example, their support of practices to act as Patient Identification Centres (PICs) and their support to study delivery in hospices and care homes. It is a misconception that research in the Primary Care setting is easy to do, but Primary Care studies can often be complex, sensitive and very difficult to recruit to, leaving the GP practice requiring a lot of support to deliver them. Without the support and dedication of our Primary Care delivery support team, many GP practices simply would not take part in research and the Network would not achieve the high levels of recruitment that we currently enjoy. It is for these and many more reasons that the CRN recognises the significant contribution that our Primary Care team provide.

### What does your vision for the future of the Network look like and how do you see primary care contributing to the continued success?

I am excited about the many opportunities for research. The development of digital technology to support clinical trials will transform the way we deliver trials, making us more efficient and meeting the needs of our population.

As you know, the way we deliver health and social care is changing. More services will be delivered in Primary Care as well as non-NHS organisations. We need to be flexible and adaptable in order to take advantage of the new opportunities for patients to have the opportunity to participate in a clinical trial.

If we get this right, clinical trials will be part of everyone's business, no matter where health and social care is delivered.

Patients will actively seek out opportunities to participate and we will continue to develop our workforce to meet these new demands. The expansion of the delivery of studies within Primary Care is an exciting opportunity and I am confident that we can work together to continue to provide a first class service for our population.

We also need to recognise the contribution Primary Care makes in all aspects of clinical research in their contribution to PIC activity and recruitment in community pharmacies and hospices.

### How do you see the Primary Care role contributing to the future success of the Network?

The future success of the Network is largely dependent on the dedication and commitment of our staff to support the timely and effective delivery of studies brought to us by our research community. I am well aware of the co-operation and collaboration that our Primary Care team have demonstrated. This has resulted in huge progress in streamlining and standardising their structure and many of their processes to improve the researcher experience, and has encouraged researchers to bring their repeated business to the West Midlands because of our excellent reputation. I am keen to support the team to build on this progress and really get them working as one team across the whole of the West Midlands, operating seamlessly together across the three localities. A Primary Care delivery support team which is dedicated, resilient, and which can quickly and positively respond to support the delivery of research in a changing Primary Care landscape, will enable them to quickly engage and support the new GP configurations and new models of healthcare providers. This will certainly add value and contribute to the wider CRN WM success.

Finally I would like to take this opportunity to sincerely thank the Primary Care team for their continued dedication and professionalism which has undoubtedly resulted in better outcomes for our population. I am looking forward to exciting opportunities ahead of us in which Primary Care will take the lead.



**46th Annual Scientific Meeting  
of the Society for Academic Primary Care**  
12th - 14th July 2017 University of Warwick



## Society of Academic Primary Care – Annual Scientific Meeting

*Emma Scott, SAPC Ambassador for Warwick University*

Following on from the successful RCGP regional symposium in May, Warwick Primary Care welcomed the Society of Academic Primary Care's Annual Scientific Meeting to the University from 12 to 14 July. The theme for this year's meeting was Pioneering Change, a particularly appropriate topic considering the challenges currently facing primary care.

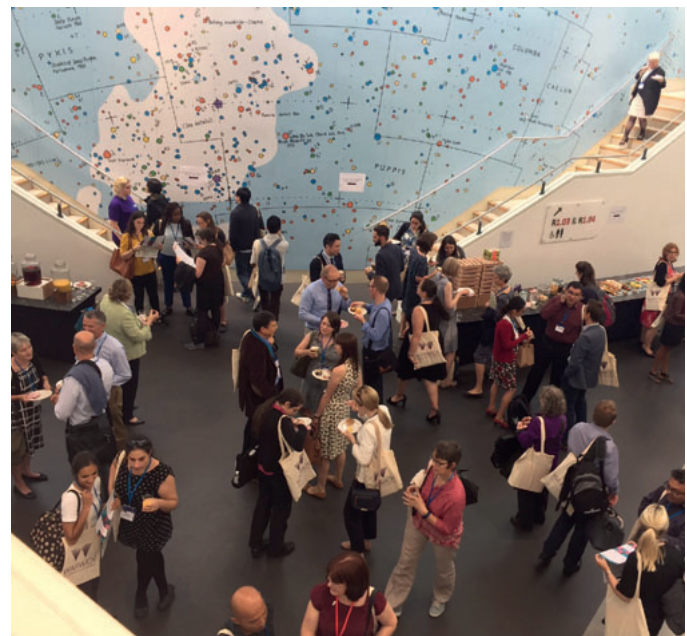
Each day featured a keynote speaker addressing over 300 assembled delegates: On Wednesday afternoon, Candace Imison (The Nuffield Trust) explored whether we should be restructuring primary care to work as a more coherent team and make better use of the skills provided by other practitioners, such as pharmacists and practice nurses, rather than focussing on how to stretch GPs time even further. After lunch on Thursday, Prof Helen Stokes-Lampard (Chair of the RCGP) enthusiastically encouraged us to rediscover the enjoyment of general practice, reminding us to share our good days with junior staff and save the moans for more senior colleagues. While on Friday morning, Prof Louise Robinson took a more clinical approach, discussing changes in dementia research and practice over the last decade. Videos of all three keynote speaker's presentations are freely available on the SAPC website: <https://sapc.ac.uk/content/asm-2017-keynote-speakers>.

Warwick Arts Centre was the venue of the fourth Helen Lester Memorial Public Lecture, which was given by Mark Gilman (Discovering Health) on Wednesday evening. Mark considered the concept of 'Discovering Health' after addiction and the very individual journey of discovery and progress that addicts make. This frank and thought-provoking talk stimulated discussions which continued to the sounds of the *Cut Loose Barbershop Group* during the buffet supper which followed.

Other social events included an early morning 5km run, a guided walk exploring the outdoor sculptures which form part of the University of Warwick Art Collection and a conference dinner at Wroxall Abbey which was followed by a Tudor ceilidh and disco.

In all, over 250 presentations were given, ranging from three minute elevator pitches to 15 minute talks and 90 minute masterclasses. The topics addressed were diverse and included distinguished papers on diabetes, dementia, polypharmacy, health education and alternatives to face-to-face consultations. In addition to sessions devoted to topics such as GP workforce, cancer, prescribing, long term conditions, children and young people, self-management, frailty and research methodology, to name just a few. These were complemented by a range of workshops and special interest groups taking place throughout the conference.

There really was something for everyone. The theme for next year's meeting is *Learning from Europe and Populations on the Move* and will be hosted by Queen Mary University of London.



## Research Design Service (RDS)



If you would like any further information, please contact us on [rds@warwick.ac.uk](mailto:rds@warwick.ac.uk) or via [www.rds-wm.nihr.ac.uk](http://www.rds-wm.nihr.ac.uk)

Do you have a good research idea that you'd like to develop further into a grant application? The RDS can help by providing methodological expertise and advice on all aspects of research design.

The RDS exists to provide help and advice to NHS researchers and others working in partnership with the NHS in preparing research proposals for submission to peer reviewed funding competitions. As the RDS is funded by the NIHR such help is provided free of charge.

**Here are some of the ways we can help:**

- Formulating research questions
- Building an appropriate research team
- Involving patients and the public
- Designing a Study
- Appropriate methodologies for quantitative and qualitative research
- Identifying suitable funding sources
- Regulatory issues
- Writing lay summaries
- Identifying the resources required for a successful project



## In Conversation with... Dr Raj Kanwar, Vale of the Red Horse, Kineton Surgery

We arrived at Kineton Surgery to be greeted by their friendly and helpful receptionist and met Dr Kanwar, who made us very welcome. The first thing that struck us on coming through the door was the surgery display board, showing the CRN research active practice poster.

Dr Kanwar is a self-confessed ‘people person’, who first became research active whilst working as an orthopaedic surgeon, where there is a high expectation of research engagement as part of the role; subsequently he has brought this awareness to his role as a GP.



### Why do research?

Research raises the profile of a practice, enhances its reputation, increases the knowledge base of the doctors and other staff, and assists with recruitment and retention of staff - particularly doctors – essential at a time of a crisis in recruitment, when other practices have struggled to recruit GPs.

Dr Kanwar mentioned the financial incentive, which provides an income used to enable protected time for research, increase the time for CPD

If you would like more information on how to get involved in research with the CRN, please contact a research facilitator in your area, details on the back page

and Research Ready etc. This combination of time and income has the overall result of reducing GP stress and allowing for extra patient time.

*“Income from research is invested back into the practice, it gives more doctor time and a better service to patients”*

Finally, the most important benefit of research participation is for the patients. Kineton is very research aware, with well motivated patients who understand the value of taking part in research. Patients like the additional time with CRN research nurses and extra health checks performed have occasionally revealed hitherto undiscovered health matters.

### Research empowerment

Dr Kanwar emphasised the practical value of research in enabling GPs to make more informed health decisions and empowering patients to understand and manage their own conditions. Management of chronic conditions can be greatly assisted by participation in a study looking at a relevant area. Recent studies include:

- HEAT, where a simple breath test can assist GPs with the most effective treatment regime
- I-WOTCH, where some patients have come off their opioids and have seen a dramatic improvement in their quality of life



*“I-WOTCH has literally changed lives”*

- FAST-GOUT, where new drug regimens have led to dramatic improvements in symptoms
- CANDID, which focussed GPs’ mind on the three-week cough, leading to better diagnoses and patient care

### Best Modernisation Award 2017

We congratulate Kineton on their success in being awarded the South Warwickshire GP Federation Best Modernisation Award for their work, led by Ben Evans, IT Manager, on introducing Intradoc and moving to a cloud-based information solution.

Practice performance and efficiency have both been improved and a more systematic way of working, saving time and paperwork, has been introduced.

### CRN support

Dr Kanwar praised both Becky Harrison and Sarah Joshi for their ‘can do’ attitude, flexibility and ease of contact. The CRN has been proactive, helpful, saves time in carrying out searches, and has always put any minor problems right with the minimum of time and maximum of efficiency.

## iFeed: Acceptability study of new Online Resource for Infant Feeding

Coventry University have developed a new digital tool to support parents with infant feeding. The resource, called iFeed, aims to empower parents to make confident choices, support them to initiate and sustain breastfeeding and/or enable safe and responsive bottle feeding when required.

It is essential that iFeed meets the needs of both parents and health professionals so your opinion is highly valued. iFeed is available for you to access now at [www.ifeedproject.co.uk](http://www.ifeedproject.co.uk) and can be viewed on your PC, tablet or mobile device. It aims to provide a trusted resource for health professionals as well as parents and their supporters. Users will initially see content with a focus on parent-infant bonding via

infant feeding. The prototype website will then allow users to receive personalised information and behaviour change techniques targeted to their role, current situation and feelings around infant feeding, including both breastfeeding and bottle feeding.

We are currently recruiting parents and health professionals to test the website and give us feedback. We are looking for GP practices in Warwickshire to act as a PIC site to invite parents to use the website. We also invite interested GPs, midwives and health visitors to view the website themselves and complete a short questionnaire and / or telephone interview. Your practice will be reimbursed for your time and resources used.



If you would like to contribute to the development of the intervention by acting as a PIC site or through the completion of a brief questionnaire and/or telephone interview, please contact your local research facilitator, contact details on the back page or Dr Naomi Bartle at Coventry University on 02477 655497 [naomi.bartle@coventry.ac.uk](mailto:naomi.bartle@coventry.ac.uk)

The ifeed project is supported by a grant from the Medical Research Council.



## Digital Communication for Health

What if you could effectively interact with your patients digitally? The need is there; Warwick is addressing it.

Digital communications can help you develop a patient centred approach to your care, maintain positive relationships with patients, catch problems early, save time and increase the ease and flexibility of your services. Our professional development course Digital Communication for Health can give you the tools required to enhance the services offered to your patients, alongside giving your patients confidence in managing their own conditions.

### Who the course is for

This course is suitable for all healthcare professionals who use, or plan to use, digital channels of communication to enhance patient care.

### Benefits

This course is based on findings of the NIHR LYNC study and will demonstrate the ways effective digital communications can help improve outcomes for patients with long term conditions.

### Course content

This two-day course has been designed to provide support and guidance on the following areas:

- The types of digital communication that work well, for whom, where and when

- Ethical issues
- Patient safety
- Costs involved
- The benefits to patients and the health service
- The development of your own plans to use digital communication channels within your clinical teams

**Course fees**  
£250

**Location**  
Warwick

**Date**  
11 - 12 December 2017

WARWICK

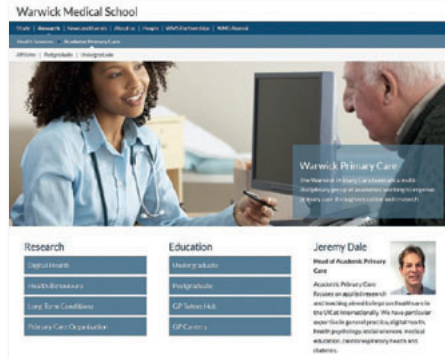
MEDICAL SCHOOL

✉ [pgt-portfolio4@warwick.ac.uk](mailto:pgt-portfolio4@warwick.ac.uk)  
<http://www2.warwick.ac.uk/fac/med/study/cpd/>  
 ☎ +44 (0)24 7657 4799



## Warwick Medical School: New Unit of Academic Primary Care (APC)

At Warwick, a new unit of Academic Primary Care was launched on 1 October 2017. It is a multi-disciplinary group of academics within the Division of Health Sciences. Led by Professor Jeremy Dale, the unit includes Professors David Fitzmaurice, Paramjit Gill and Robert Walton and their teams together with Dr Sue Davies and those involved in delivering GP undergraduate and postgraduate teaching. The unit provides a focus for world-class primary care teaching and research, and also hosts the CRN primary care specialty team for West Midlands South.



The unit aims to provide an environment for:

- Excellent primary care research that addresses key challenges facing the NHS, and supports growth in primary care research participation in the West Midlands
- Clinical and non-clinical primary care academic capacity building, research training and professional development
- Integrating primary care and community based teaching at both undergraduate and postgraduate levels

If you would like further information, or would like to become involved with the APC, please contact the unit administrator, Helen McGowan email: [h.mcgowan@warwick.ac.uk](mailto:h.mcgowan@warwick.ac.uk), phone: 024 7615 1968

## One Million Patients Recruited!

To mark the achievement that one million patients have taken part in research since 2006, including 175,000 from the West Midlands, the NIHR provided celebratory banners for display in practices. The first three to be selected in West Midlands south were Bedworth Health Centre, Castle Medical Centre and Jubilee Health Centre. We would like to thank all practices that have taken part, and helped to reach this research milestone.



## Becky Harrison

### Senior research facilitator



We are pleased to welcome Becky Harrison as the new senior research facilitator for the West Midlands south area. Becky will be based at Warwick Medical School where she was previously employed as a research facilitator.

Her background includes a PhD at Birmingham and extensive experience in working with practices to promote the uptake of research in primary care. When not at work she enjoys country walks and travel.

For Becky's contact details, see back page.

## Practice Praise

### Promoting Research

**Ombersley Medical Centre** for becoming much more research active, undertaking All Heart and HEAT; special thanks to Dr Gemma Moore and Carola Elliott.

**Northumberland House Surgery** for Dr Appanna's enthusiastic approach to research.

**Alton Street Surgery** who have recently re-engaged in research after a break and are looking forward to working again with CRN staff.

**Priory Gate Practice and Broad Street Surgery** for being very research active this year, taking on all studies offered.

### New to Research

- **Merstow Green Medical Practice** have successfully undertaken FAST Gout
- **Crabbs Cross Medical Centre**
- **Link End Surgery**
- **Cradley Surgery**

### Special Congratulations

**Hastings House** is the highest recruiting practice to All Heart in the West Midlands

### All Heart

**Stanmore House Surgery** where an efficient and well organised practice has successfully delivered a 100% attendance rate over 18 clinics.

**Forrest Medical Centre** for the smooth running of this study, especially thanks to Dr Day.

### HEAT

**New Road Surgery, Bromsgrove** with a very high number of patients interested in HEAT and where staff are all organised, efficient and welcoming, especially Julie Yates



## Summary Results: Patient Research Experience Survey 2016/17

These are summary results of a patient survey about experience of participating in clinical research. The survey was carried out by Local Clinical Research Networks across England and the results were collated and analysed nationally. The local surveys included the same or very similar core questions and a free text box. The survey followed a pilot in 2015/16.

The number of respondents to the survey (3,320) was much higher than the original pilot (597) which means the data is very reliable and confirms the findings from the pilot.

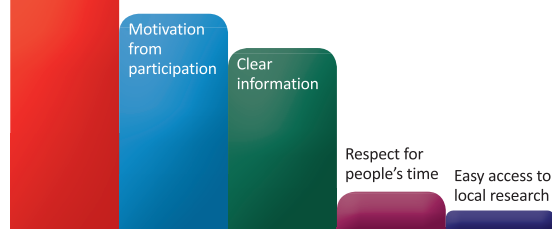
### The feedback showed that:

 **90%** of patients had a good experience of participating in clinical research

 **86%** of patients would be happy to take part in another research study

### Relationships with research staff

We looked carefully at what people said to us in their free text responses to the survey. Some common themes emerged about what people found most important in their experience of research. We also noted the number of mentions belonging in each theme:



### What the themes mean in order of emphasis

#### Research Staff

The feedback from research participants emphasized the friendliness, professionalism, knowledge, approachability, helpfulness, and respectfulness of staff being most important. This strong appreciation of staff was also expressed frequently in comments of those who had indicated that they were unlikely to take part in another research study.

**LEARNING:** Good working relations with staff are clearly key to good patient experience of a research study.

#### Motivation

Responses revealed much about the importance of motivation to patients for participating in research. In particular:

- altruism and improving medical knowledge
- possibility of improving own health condition
- better medical monitoring
- learning about a medical condition

**LEARNING:** It is important to acknowledge and appreciate the patient's motivation for participating in a research study.

#### Information

Feedback showed that good and timely information is very important to the patient's journey through a research study. This included information about the:

- research study itself
- practical arrangements for participating such as reminders etc. for visits
- progress of the research study (particularly a long one) and any interim findings
- results at the end of the research study

**LEARNING:** Having the right information at the right time is important to feeling fully engaged.

#### Time

This was mentioned in a good number of comments in the feedback, particularly about timing of research appointments and waiting time whilst on a visit.

**LEARNING:** It is important to respect the patient's time given to participate in a research study.

#### Access

There were also a range of comments generally about access and these tended to be about:

- flexibility of timing
- location
- travel
- parking
- disability access

**LEARNING:** There are a number of practical factors that can affect experience in attending a research study and can significantly contribute to the burden of doing so.

For more details about the background, the questions and full results of the Patient Research Experience Survey please read the full report which is available at <https://www.nihr.ac.uk/why-research-matters> or on request from Mana Golsorkhi on 020 3328 6707 or email: [crnppie@nihr.ac.uk](mailto:crnppie@nihr.ac.uk).

## Patient Research Ambassadors needed to Support Primary Care Research

The Clinical Research Network West Midlands Primary Care PPIE team are supporting the roll out of the NIHR Patient Research Ambassador Initiative.

Patient Research Ambassadors (PRAs) promote health research from a patient point of view. They could be a patient, service user, carer or lay person who is enthusiastic about health research and willing to communicate that to other patients and public as well as healthcare professionals.

There are a number of PRAs who help to raise the profile of research in an acute setting. We are keen to establish PRAs to help local practices and health centres, promote research and work with existing groups such as Patient Participation Groups in the region.



If you would like to find out more information about the patient experience in primary care research survey or are keen to establish patient research ambassador at your organisation then please contact your local research facilitator.



You can also contact Moe Shaikh, CRN WM Patient and Public Involvement and Engagement Cross Cutting Theme Lead on 024 76430165 or email [mohammed.shaikh@nihr.ac.uk](mailto:mohammed.shaikh@nihr.ac.uk) or contact Mary-Anne Darby, CRN WM Head of Patient and Public Involvement and Engagement in Research on 01902 447193 or email [mary-anne.darby@nihr.ac.uk](mailto:mary-anne.darby@nihr.ac.uk).

## Research Codes for Primary Care



Dr Mark Porcheret

Clinical coding of patient consultations is standard practice in primary care; however the use of codes for research purposes in general practice has to date been variable. Research is part of core business within the NHS, so it is essential that NHS staff have the tools they need to code research activity in general practice computer systems in a clear and consistent way with generic research codes (which could be specific to an individual study via a study ID) for recording research activities.

### Benefits of generic research codes to:

#### Primary care sites

- Patient identification: easy identification of patients approached about or entered into studies. Codes ensure a record of research participation remains in the patient's lifelong electronic record, making patient follow-up easier
- Preventing multiple approaches: ensuring patients aren't sent multiple requests to take part in the same study, or in different studies. Sometimes, multiple approaches may be appropriate and practices will be able to monitor this activity
- Safety: enabling swift identification of patients who need to be contacted about a specific study
- Administration: reduces paperwork, saves time, ensures easier monitoring and searching in patient records, reduces the need for free text. National research codes allow future proofing of coding, as systems develop and change and data is migrated across systems.
- Other: helpful in audit, making it an easier process and improving data quality

## NIHR CRN

- Aid mapping of activity: to ensure practices can better track activity and provide more accurate information to the network
- Patient Identification Centre (PIC) work/screening: using codes will allow practices to capture PIC activity and to identify patients participating in specific studies, e.g. if participation in one study is an exclusion criterion for another
- Recruitment: pop-ups during consultations can alert clinicians about studies a patient may be eligible for, potentially enhancing recruitment



A manual has now been launched, incorporating the work of the former Primary Care Research Network (PCRN) working group and, in particular, Dr Mark Porcheret, to whom we extend our grateful thanks for his sterling work in steering the process through to completion.

If you would like more information about research codes for primary care, or would like to receive a copy of the full manual, please contact your local research facilitator, details on the back page.

## The Role of GP Receptionists: A Research Study

Michael Burrows, Ian Litchfield, Nicola Gale and Sheila Greenfield

The roles of the GP receptionist are varied and essential to the smooth running of the practice. As well as undertaking administrative and clerical duties such as filing, maintaining medical records and making appointments, they also undertake



functions more directly related to patient health, such as booking appointments, communicating test results and managing repeat prescriptions. However the complexities of primary care are increasing and these responsibilities are placed on staff without formal training. This has clinical consequences for patients and medico-legal concerns for practices. Funded by the Health Foundation, we aim to explore in greater detail the parameters of the GP receptionist's role in modern healthcare, exploring the scope of their current activities and ultimately identifying areas that might benefit from targeted support. Further details can be found in our published protocol.

### Getting involved

We are currently recruiting participants and would like to encourage receptionists across the West Midlands to complete our questionnaire. This will take only a few minutes and includes questions about the nature of current responsibilities, and their interactions with colleagues and patients. It can be accessed via: [https://bham.onlinesurveys.ac.uk/gp\\_receptionist-survey\\_v1](https://bham.onlinesurveys.ac.uk/gp_receptionist-survey_v1). The second phase involves speaking with patients and a broader cross-section of staff to gather a range of perspectives on the role.

If your practice is interested in being involved in either phase or if you would like any further information about our work please contact Michael Burrows; [Mjb538@bham.ac.uk](mailto:Mjb538@bham.ac.uk) or on 07528 528868.



## The Diagnostic and Prognostic Value of the Symptom of Shortness of Breath in Primary Care: A Cohort Study



### Background

When a patient consults their GP, the GP may record a symptom (e.g. shortness of breath) rather than a diagnosis (e.g. asthma) in the patient's computerised record. This may happen if the GP regards a symptom as representing a self-limiting illness, or the diagnosis is not clear at the time of an initial consultation.

Complaints of breathlessness and wheeze are common reasons why patients consult their GP, and may simply be a short-term and minor problem, or could be an early sign of chronic obstructive pulmonary disease (COPD), asthma, or ischaemic heart disease (IHD). The similarity of symptoms related to these conditions may make their diagnosis at initial presentation difficult, and often requires a number of tests.

### The study

This was a study of adults aged  $\geq 18$  years, performed within the Clinical Practice Research Datalink (CPRD) – a database drawing on GP records in England.

### Results

In this study, we found a much higher rate of COPD, asthma and IHD diagnosis in the next six months in patients presenting with an undiagnosed breathlessness/wheeze symptom for the first time compared to patients without a recorded breathlessness or wheeze symptom. This suggests these symptoms are strong markers that helped GPs to make a diagnosis. However, there were still higher rates of COPD, asthma and IHD diagnosed after the first six month period. We think this increased rate may be partly explained by some in diagnosis.

Some patients were initially prescribed drugs relevant to their future diagnosis despite the notes not having a diagnosis label recorded, but two-thirds of patients did not receive potentially appropriate medication in the initial six months after presenting with a breathlessness or wheeze symptom. This may represent a missed opportunity for early management.

Patients who received no relevant management in the first six months still had noticeably increased risks of COPD, asthma, and IHD. Furthermore, it was found that patients with a breathlessness or wheeze symptom had increased death rates.

### Conclusions

These findings suggest that presentation to primary care of breathlessness and wheeze can be an early indicator of later diagnoses of asthma, COPD and IHD, and also an indicator for earlier mortality.

Primary Care clinicians should consider more targeted investigations, monitoring and follow-up when patients initially present with symptoms of wheeze or breathlessness, to ensure accurate diagnosis, appropriate management and health and lifestyle advice are given to patients as early as possible.

### Patient and Public Involvement and Engagement (PPIE)

We held a number of PPIE meetings, members from the local 'Breathe-Easy' group, where the study idea, analysis and results were discussed. The study team is very grateful for the contribution of the PPIE group.

### Outputs

- Two papers are in preparation for submission to academic journals
- Two presentations of the results have been made at academic conferences (Society for Academic Primary Care, 206 and 2017)
- Summary of results sent to local Clinical Commissioning Groups (as suggested by the PPIE group)

## RCGP MIDLAND FACULTY ANNUAL EDUCATION, RESEARCH & INNOVATION SYMPOSIUM

# 2018

### Thursday 17th May

This interactive day is a must for students, GPs, registrars, researchers, and allied health professionals. The event aims to **inspire, translate and innovate** primary care research by showcasing current research. Delegates will be able to present their research and find out more about how to further your career by getting involved in primary care research and innovation.

#### KEYNOTE SPEAKERS

**Professor Roger Jones**  
Editor, BJGP

**Professor David Fitzmaurice**  
University of Warwick

**Professor Helen Stokes-Lampard**  
Chair, RCGP

**Dates for your diary**

- Abstract Submission NOW OPEN!
- Abstract Deadline: 25th February 2018
- Registration Deadline: 30th April 2018

**Price (includes lunch and refreshments)**

- Non-RCGP Member: £50.00
- RCGP Member: £45.00
- AIT: £35.00
- Student: £10.00

**Details**

- Date: 17/05/2018
- Time: 9.30am-4.30pm
- Venue: The Ballroom, Keele Hall, Keele University, Staffordshire, ST5 5BG
- Register online NOW!

[www.keele.ac.uk/rcgp2018](http://www.keele.ac.uk/rcgp2018)



# Local Contacts

For more information about any study, or further information about anything else in Participate, please contact your local research facilitator



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