Clinical Research Network
West Midlands

NHS
National Institute for
Health Research

Winter 2017

Edition No. 2

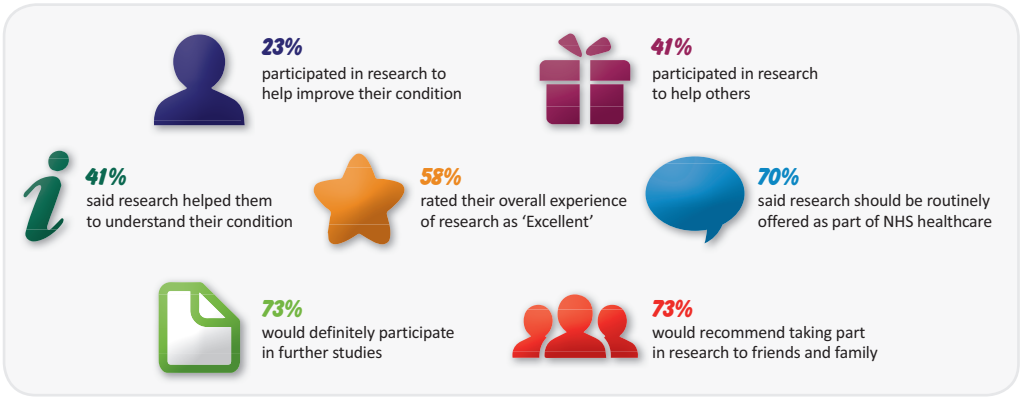
PARTICIPATE

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@nihr.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 or jenny.oskiera@nihr.ac.uk

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

Contents

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

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

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.

Chronic Headache Education and Self-management Study (CHESS)

CHESS Chronic Headache Education and Self-management Study

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

We are currently recruiting people aged ≥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 CHESS 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 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.

Health in the West Midlands Study (HILL)

We will survey a sample of 27,000 patients aged 35 and over registered with general practices across the West Midlands.

Better health intelligence is needed for the common health conditions that cause the greatest amount of disability in the United Kingdom (UK). Primary care has a critical role in responding to this challenge and electronic health records (EHR) from this setting are increasingly recognised as an important driver for public health policy, clinical practice, and research. However there is a need to move beyond recorded processes of care to incorporate information on patient health-states, experiences and outcomes like the impact on work, function and quality of life.

The findings of this study will be used to inform plans for health services with an overall aim of improving the quality of life for the population of the West Midlands and beyond.

The study is due to start in November 2017 and will continue until the end of March 2018.

Study Lead: NIHR CRN research facilitator, Natalie Burgess

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

Welcome to Helen

My name is Helen Lee and I joined the CRN West Midlands primary care team based in Telford, as Admin Assistant in July. I am a psychology graduate, having studied at the University of Chester. I continue to have a keen interest in psychology and would like to study this subject further in the future.

I have previously worked with adults with autism in a residential setting and upon completing my degree, worked for the charitable organisation, Barnardos, helping to run one of their stores as a store associate.

I shall be providing administrative support to the Clinical Research Manager, team of Research Facilitators and Research Nurses at the Telford office as well as supporting the Primary Care Study Support Manager with wider network administrative duties. I am also the Google Champion for Keele.

Outside of work I have an interest in music, particularly playing the piano. At university I also developed an interest in the sport of fencing, which I hope to continue in the near future. I am excited to be working for the CRN WM and am grateful to be working with such a welcoming and friendly team. Email: helen.lee@nihr.ac.uk

ACT-FLARE – Coming 2018

ACuTe FLAREs and flare phenotypes in knee osteoarthritis: an observational case-crossover study to improve recognition and advice for prevention and management.

This study aims to determine the course and consequences of acute flares in knee osteoarthritis. It will also aim to identify high-risk patient profiles and triggers that will direct future prevention and management for patients and healthcare practitioners.

Practice involvement

- Practices will run a search to identify adults aged 40 years or over with knee pain/osteoarthritis
- GPs will screen the list of eligible patients and send invitations letters out
- Interested patients will respond to the study team who will send patients a web based questionnaire to complete

Inclusion criteria

- Male or female aged ≥ 40 years
- Consultation for knee OA or knee OA-related joint symptoms in the last two years
- Daily access to an email account and to the internet (laptop, desktop, tablet, or smartphone)

i-WOTCH

In the north locality a number of practices have agreed to participate in the i-wotch study from the East Staffordshire CCG area. Initiations are being booked in and we look forward to confirming these practices and moving forward to the next phase of screening, mailing and recruiting patients. One more practice is needed in the area who use EMIS Web or SystemOne to reach the target of 50,000 total practice patient population. We currently have 43,677 so are very close to achieving this with just one more practice.

If any practice in East Staffordshire is using EMIS Web or SystemOne and hasn't yet expressed an interest, please contact your local research facilitator, Gerri Mulcahy contact details on the back page.

RIsk COmmunication in NHS Health Checks (RICO)

The aim of this study is to explore practitioner and patient perception of cardiovascular disease (CVD) risk when using an existing 10 year risk calculator (QRISK2) with a new lifetime risk calculator; the associated advice or treatment offered by the clinician and the response of the patient.

Half of the practices will be randomised to QRISK2 (i.e. usual practice) and half to use the new risk calculator.

General practices within the West Midlands will be invited to take part in the study if they meet the following inclusion criteria:

- Health checks are already being delivered within routine practice
- Practices already use the QRISK2 percentage risk score within health check consultations
- Practices deliver health check consultations within specific clinics, or are willing to adopt this practice to facilitate data collection
- Be signed up to the Research Site Incentive (RSI) Scheme implemented by the CRN to ensure the GP practice is 'Research Ready'
- Provide necessary practice-level consent

CRN activity

- Run search of clinical system to identify eligible patients
- Stratify list as per study team requirements
- Mailout 200 - letter printed at practice, and Patient Information sheet/Consent Form/envelope and stamps provided by study team
- Tag invited patients on EMIS
- CRN research nurse to contact patients who have not opted out - obtain verbal consent and book health check appointment at practice
- Send out letters to patients who didn't opt out once clinics are full to advise them that this is no longer available as part of the study, and provide details of how they book at standard NHS Health Check
- CRN research nurse to make a reminder phone call the day before clinics to patients booked in.

Practice activity

- Involved staff to attend initiation visit/training run by study team from Staffordshire University
- GP to screen list of eligible patients
- Nominated contact to receive calls from patients wishing to opt out of study and tag as declined on EMIS
- Practice nurse and/or healthcare worker to facilitate one to two dedicated clinics (or one full day) per week for approximately four weeks
- Practice nurse and/or healthcare worker to tag consented patients when attending health check guidance document provided (if you don't feel that this is feasible a CRN research facilitator can come in and batch tag retrospectively)
- Allow NHS health check clinics to be video recorded (by Study Team) - until 20 consultations have been recorded
- Practice nurse/health care worker to attend video-stimulated recall interview lasting approximately one hour <2 weeks post consultation (consent will be obtained from practitioner for this)
- Allow CRN or study team to extract medical record review of consenting participants (minimum 12 weeks post NHS health check)

Study Team Incentive:	£1000 per Practice
RSI Scheme payment:	£900 (Grade three study)
Study Support costs:	Level One GP screening of list (approx. 30p per patient screened)
Recruitment status:	October 2017 - October 2018
Chief Investigator:	Dr Christopher Gidlow, Associate Professor, Staffordshire University
Sponsor:	Staffordshire University
Funder:	National Institute of Health Research

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

OWL
Coming 2018

Opioids, Women & Libido

There has been a trend towards increased opioid prescribing in primary care

In women, it is recognised that illegal dependent opioid use can be associated with reproductive and sexual dysfunction (low libido, sexual dysfunction and menopause). The picture is less clear with respect to prescription opioids.

The primary aim of this study is to investigate associations between prescription opioid use and low libido in women (18-45) with a musculoskeletal condition.

Principal investigator: Emily Wersocki (Keele University).
Location: Looking to identify up to 20 practices in the West Midlands

Practice involvement

- Search of clinical system to identify potentially eligible patients by your CRN research facilitator
- Screening of patient list by clinician
- Mailing invitation letters to identified patients with questionnaire

OWL

INCLUDE: INtegrating and improving Care for patients with infLammatory rheUmatological DisordErs in the community: A pilot randomised controlled trial

Study background

Patients with inflammatory rheumatic conditions (such as rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, polymyalgia rheumatica and giant cell arteritis) are at an increased risk of common comorbidities such as cardio-vascular disease, osteoporosis, anxiety and depression. These are often not recognised or treated and can lead to increased morbidity and mortality. Developing an innovative nurse-led model of care within primary care may improve outcomes for these patients.

INCLUDE is a two-arm pilot cluster randomised controlled trial which aims to evaluate the feasibility and acceptability of a nurse-led integrated care review for people with inflammatory rheumatological conditions in primary care

What will the study require of practices?

- Consent to practice being randomised to one of two trial arms (intervention or control)
- Search (or allow CRN staff to search) practice list to identify patients with an inflammatory rheumatic condition
- GP to screen list to identify patients not suitable to participate
- Mail (or allow CRN staff to mail) Baseline Questionnaire pack & reminders to potentially eligible patients
- Provide access to practice systems (EMIS Web) & clinic facilities for a study nurse e.g. ½ day per week in study period (intervention practices only)
- Conduct (or allow CRN staff to conduct) brief Medical Record Review

What are the benefits of participating?

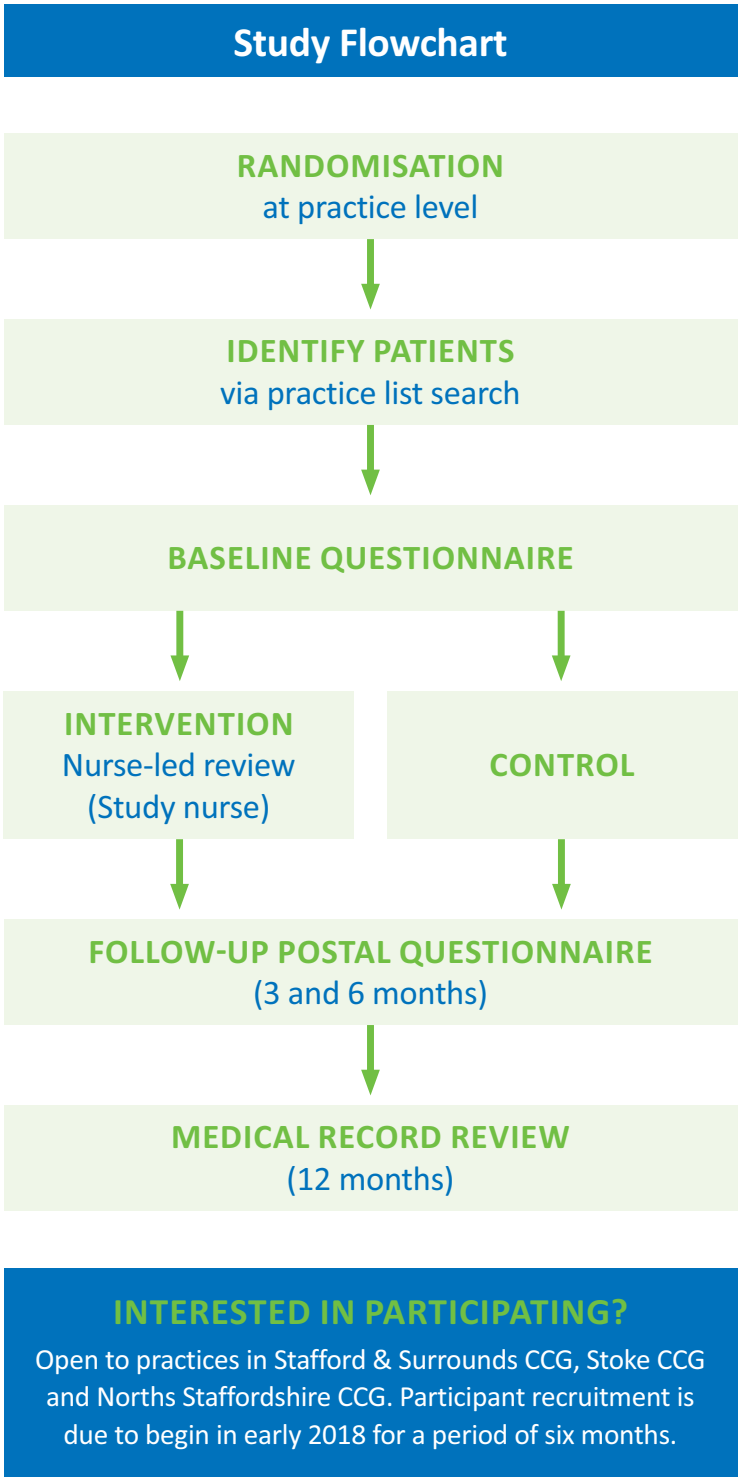
For patients:

- Provides an opportunity to take part in research to help improve care for their inflammatory rheumatological condition(s)

For practices:

- Participation in research can be reflected upon as part of appraisal
- Reimbursement will be provided to meet costs for search, screen, baseline mail out and medical record review
- CRN RSI Grade 1 study equating to a payment of £300 (dependent on completion of all listed study related tasks)

Study Flowchart



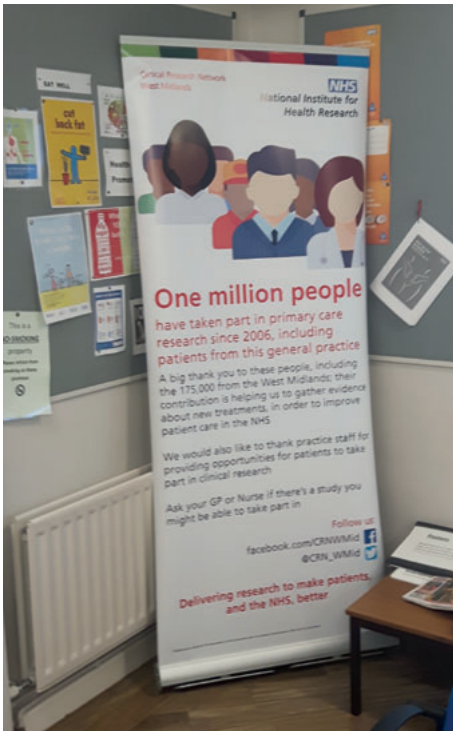
INTERESTED IN PARTICIPATING?

Open to practices in Stafford & Surrounds CCG, Stoke CCG and Norths Staffordshire CCG. Participant recruitment is due to begin in early 2018 for a period of six months.

If your practice is interested in taking part, please contact your local research facilitator Jen Titley, details on page 12. If you would like further information about INCLUDE, please contact Dave Goddin, Study Coordinator on 01782 732926 or d.goddin@keele.ac.uk

The North Staffordshire Health Survey

A general health questionnaire looking at common musculoskeletal conditions that cause the greatest amount of disability in the United Kingdom (UK) was sent to 25,616 patients across North Staffordshire.



There was a pilot (two practices) and a main study (11 practices)

The pilot was undertaken at two practices mailing 9,262 patients. The response rate was 30%. In order to increase the response rate for the main study the local Research Facilitators Natalie Burgess and Gerri Mulcahy ensured all practices involved were provided with a study poster for their waiting room and an electronic slide to show on their screens. The practices were also asked to display on social media if possible. We also generally promoted research in these practices by making sure a research plaque was displayed and some practices had a large poster or pull up banner.

For the main part of the study 11 practices were involved mailing 16,354. The survey was sent to all patients over 35 with a recent consultation for a musculoskeletal condition of interest, plus a random sample of adults in the registered practice population.

The response rate for this study has been excellent, with more than 50% of patients responding. Thank you to all the practices and patients for their help with this study.

Arthritis Research UK

The findings of this study will be used to inform plans for a national system of musculoskeletal health intelligence that is capable of providing timely, sustainable, relevant key data on musculoskeletal health, disease, risk, and outcomes for the public, healthcare professionals, and policymakers.

Thank you to all the following practices for their involvement:

- Trent Vale Medical Practice
- Baddeley Green Surgery
- Mayfield Surgery
- Orchard Surgery
- Waterhouses Medical Practice
- Moorlands Medical Centre
- Park Medical Centre
- Biddulph Doctors
- Belgrave Medical Centre
- Kingsbridge Medical Practice
- Millrise Medical Centre
- Moorcroft Medical Centre
- Wolstanton Medical Centre

Total bUrDen Of psoRiasis

TUDOR

GP practices in the North Midlands area (Staffordshire, Stoke, Shropshire and Wolverhampton) are invited to participate in the TUDOR study as a 'Patient Identification Centre'.

Inclusion Criteria for participants:

- Age 18-70 at time of recruitment
- Have a Read Code for psoriasis in primary care record at any time prior to date of recruitment
- Able to provide written informed consent
- Be willing to attend a clinical assessment by the research team at the Haywood Hospital

Royal United Hospitals Bath NHS
NHS Foundation Trust

How will the practice be involved?

- Search to identify potentially eligible patients at the practice (using disease specific read codes)
- GP/s at the practice will be given the opportunity to screen the list of potentially eligible patents for any patients they believe are not appropriate to be contacted about the study
- Invitation letters via Docmail
- Interested patients will respond directly to the study team who will carry out the majority of the remaining study activity

Reimbursement will be available to cover the cost of research activity.

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

iPCHS Newsletter

Keeping you in the loop.

Keele University's Research Institute for Primary Care and Health Research brings you the latest in their September 2017 e-newsletter **http://bit.ly/2iyT6Vm**.

To make sure you're always up to date, follow them on their social media channels.

Summary Results: Patient Research Experience Survey 2016/17

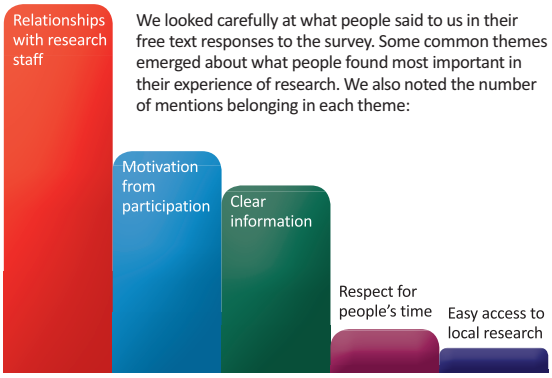
These are summary results of a patient survey about experience of participating in clinical research. The survey was carried out by Local Clinical Research Networks across England and the results were collated and analysed nationally. The local surveys included the same or very similar core questions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

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



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.

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 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.

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. 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 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 ≥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)

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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