



**NIHR IMPERIAL CLINICAL RESEARCH
FACILITY PATIENT AND PUBLIC
INVOLVEMENT (PPI) PANEL**

GLOSSARY OF RESEARCH TERMS

Glossary of Research Terms

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Introduction

This booklet is a Glossary of terms and words often used in research studies in the Centre. We hope the Glossary will assist anyone who needs a quick collective point of reference and in particular assist our Research User Group (RUG) in their important contribution to our work. Their role in helping researchers, sitting on steering committees, and commenting on documentation going out to the public often inevitably involves specialist research or medical terminology. The Glossary is not an exhaustive reference but we hope it will help RUG members with their work.

Explanation of Terms

A:

A Priori: A Latin term meaning 'from the earlier' it refers to knowledge which is based on logical reasoning or theory, which is not supported by scientific proof. Researchers frequently use this term to describe decisions about how they will analyse data before the research occurs.

Abstract: A brief summary of the main features and results of a research study.

Acute Attack: Acute is the medical term for an illness or medical problem that begins and progresses rapidly. It may also refer to an illness that begins and ends quickly.

Adherence Enhancing Toolkit: A comprehensive range of assessment and treatment techniques (or 'tools') that are made available to physiotherapists in the trial, including for example ways to identify patients' own exercise goals and support them to maintain their chosen activities over time. Some of the techniques are used by physiotherapists with patients and some are used by patients.

Adherence to Treatment: The following of a recommended course of treatment by taking all prescribed medications for the length of time necessary.

Adrenal Gland: A small gland located on top of the kidney. The adrenal glands produce hormones that help control heart rate, blood pressure, the way the body uses food, the levels of minerals such as sodium and potassium in the blood, and other functions particularly involved in stress reactions.

Adrenal Suppression: A condition resulting from the suppression of cortisol secretion by the adrenal glands.

Allopurinol: A drug used in the treatment of gout, a disease that is characterized by severe inflammation in one or more of the joints of the extremities.

Analgesics: A member of the group of drugs used to relieve pain. Also known as a painkiller.

Analysis: Data analysis involves examining and processing research data, in order to answer the questions that the study is trying to address. For some types of research this will mean looking at numbers and statistics to identify patterns. For other types of research it will involve looking at the words of what people have said in interviews and drawing out the main themes. Analysis is often done with specialist computer software.

Anonymised Data: Data from which the patient cannot be identified. The name, address, and full post code must be removed together with any other information which, if combined with other data seen by researchers, could identify the patient. Unique numbers may be included only if researchers do not have access to the 'key' to trace the identity of the patient.

Anticoagulants: Anticoagulants are a class of drugs used to prevent blood clotting.

Anti-inflammatory drugs: Also known as non-steroidal anti-inflammatory drugs (NSAIDs). Anti-inflammatory drugs are a class of medication used to prevent inflammation (i.e. swelling and redness) of muscles and joints, and to reduce pain.

Arm: A group of patients receiving a particular treatment (or placebo) in a clinical trial.

Arthritis Research UK Clinical Studies Groups: Groups set up by Arthritis Research UK to review and fund proposals relating to clinical trials of arthritis. ARUK currently has Clinical Study Groups in 8 arthritis-related disease areas. These groups will only fund research if it fits with the ARUK's strategic priorities.

Arthrocentesis: (See Joint Aspiration)

B:

Barriers: A barrier is something that stops somebody from doing something. So, for example, a barrier to visiting your GP about joint pain may be the fact that you live a long way from the surgery and you don't drive so you find it hard to get to the practice.

Baseline Measure: A baseline measure is a patient symptom or characteristic (e.g. pain, blood pressure) that is measured at the beginning of the research study, before any treatment starts.

Baseline Questionnaire: A questionnaire used at the beginning of a research study (see Baseline Measure).

Behavioural: The way in which a person, or group behave in response to a specific set of symptoms or conditions.

Bias: Bias is when a particular research design or analysis is likely to favour a particular outcome and would, therefore, make those results unreliable. It is important to avoid bias in health research as it can influence the results and could lead to unsafe or ineffective treatments being licensed for use, or useful treatments being overlooked.

Biological Effects: How a treatment or drug affects the makeup of body systems or organisms.

Biomedical Model: A model of illness that describes a person's condition, in terms of how the body works and functions. It does not include psychological and social factors.

Biometrics: Also called biometry and is the measuring of human body characteristics

Biostatistics: The analysis of human body characteristics or health data using statistical methods. Biostatistics maybe used to help learn the possible causes of a disease in a certain group of people.

Blind to Treatment Allocation: Refers to people who do not know what treatment a study participant has been given.

Blinding: Blinding means that trial participants do not know which treatment they are receiving. This helps prevent bias. Double blinding refers to the participant, their doctor and researchers running the trial not knowing which treatment is received by which group until all data have been recorded. Single blinding means that the patient does not know which treatment they are receiving but their doctor and or researcher does.

Body Manikin: A model of the human body commonly used for exhibiting the parts and organs, their position, and relations. Used on questionnaires to show where a patient's pain is. (A picture of a body, on which patients can mark the parts that are painful).

Brand Name: A name given to a drug that a company has a patent on for a period of time. For example "Prozac". When the patent finishes other companies are then able to produce it under a generic name.

C:

Calibration: To check, by comparison with a standard, the accuracy of a measuring instrument of any type.

Capturing present care in a coded form: When you visit your GP about a health problem the GP will record your visit on the computer, and will give a code to the problem you have consulted for. This is a way to log all of the visits to a general practice and this log can be used for research. (See Read Code)

Care Pathways: A care pathway is a care plan within an agreed time frame, written and agreed by a team including, doctors, nurses and physiotherapists.

Carer: A carer is a relative, friend or partner who provides (or intends to provide, or used to provide) care to another person on a regular basis.

Catastrophising Scale: A questionnaire completed by patients asking about how much exaggerated negative feelings they have related to their pain.

Categorisation: Grouping objects into categories, so they can be compared and understood.

Causality: The relationship of cause and effect.

Characteristic: A certain feature or trait (e.g. blood type).

Chief Investigator: A senior researcher who takes overall responsibility for the design, conduct and reporting of a study.

Chi Square Test: A statistical test used to compare observed data with data we would expect to find according to a specific hypothesis.

Chronic Conditions: A chronic condition is a human health condition or disease that is persistent or otherwise long-lasting in its effects. Also known as a long term condition.

Chronic Pain Risk Score: A questionnaire which measures the risk of someone developing long term (chronic) pain.

Chronological Order: Means that you list events in date order, starting with the earliest date and finishing with most recent.

Clinical Engagement: This means working with clinicians on aspects of the study. So it might mean talking to general practitioners, physiotherapists or nurses about the methods to be used, or inviting people to be on a research study team.

Clinical Indicators: These are measures of the process, structure and/or outcomes of patient care.

Clinical Leads Portfolio Meeting: The clinical portfolio group is a management group in the Research Institute of Primary Care and Health Sciences. This group is made up of people who lead research programmes. They meet every month to discuss the research that is being undertaken in the Centre.

Clinical Trials: These are research studies involving patients, which compare a new or different type of treatment with the best treatment currently available. They test whether the new or different treatment is safe, effective and any better than what already exists. No matter how promising a new treatment may appear during tests in a laboratory, it must go through clinical trials before its benefits and risks to actual patients can be really known.

Cluster Trial: This is study where groups of practices or departments or geographical regions are randomly allocated to receive a new intervention (i.e. new treatment or care) or to continue with their normal care. G.P. Practices are randomly allocated, not individual patients. All the patients in that practice receive the approach allocated to their practice. If they're registered in a 'continue as normal' practice all eligible patients receive their usual care. If they're registered

in an 'intervention' practice all eligible patients are offered the new intervention. Therefore treatment is not allocated on an individual patient-by-patient basis, but by practice (department). (See Intervention)

Co – occurrence: An event or situation that happens at the same time as or in connection with another.

Co applicant: When researchers request money for research funding they fill in grant applications. The people who write the grant application are called co-applicants. When the team have had PPI within the planning stage of the application, they may ask a member of the PPI group to be a co-applicant.

Cochrane Review of Best Practice: Cochrane Reviews are systematic reviews of research in human health care and health policy, and are internationally recognised as the highest standard in evidence-based health care. They investigate the effects of interventions for prevention, treatment and rehabilitation. They also assess the accuracy of a diagnostic test for a given condition in a specific patient group and setting.

Coded Thematically: Thematic analysis in its simplest form is a categorising qualitative data. Researchers review their data, make notes and begin to sort it into categories. It helps researchers move their analysis from a broad reading of the data towards discovering patterns and developing themes. (See Qualitative Data)

Coexist: To exist together at the same time or the same place.

Cognitive Impairment: Problems with mental abilities (such as thinking, understanding, knowing and remembering).

Cohort: A group of people identified for study and clearly defined by certain factors such as the area they live in. Can also be used to describe a study type.

Cohort Study: An observational study in which a defined group of people (a cohort) is followed over time and outcomes are compared in subsets of the cohort who were exposed.

Colchicine: A medication which may be prescribed for Gout treatment.

Collaboration (in the context of user involvement): Active, on-going partnership with members of the public in the research process. Members of the public might take part in an advisory group for a research study, or collaborate with researchers to design, undertake and/or disseminate (share) the results of a research study.

Commissioner (research): The person or organisation who asks for a piece of research to be carried out.

Commissioning (research): This involves deciding the priorities for research, and awarding funding for research studies.

Common Instruments: Instruments are questionnaires that people fill in when they are part of a research study. These instruments/questionnaires may be several pages in length and will ask people to tick boxes to explain e.g. how much pain they have felt in the last week. When studies

use common instruments it means they are using the same questionnaires, so asking the same questions to all of the participants. (See Surveys)

Commonality: The possession of a certain attribute or set of shared features or attributes.

Comorbidity: Is the presence of one or more additional conditions to the main disease under investigation.

Conceptualise: Means to form a concept (i.e. thought or idea) about something in your mind.

Confidence Intervals: There is always some uncertainty in research. This is because a small group of patients is studied to predict the effects of a treatment on the wider population. The confidence interval is a way of expressing how certain we are about the findings from a study, using statistics. It gives a range of results that is likely to include the 'true' value for the population.

Confidence Levels: A measure of how reliable a statistical result is, expressed as a percentage indicating how likely the result is correct.

Consecutive Patients: A series of patients with a defined disorder.

Consensus: A general agreement among the members of a given group who all exercise some discretion in decision-making and follow up action.

Consensus Conference: A consensus conference is a type of meeting where people are brought together to discuss and agree on a particular issue, for example priorities for research.

Consensus Study: This is a type of study that asks a number of participants to offer their opinion or expertise on a topic initially and then by sharing those opinions with the rest of the group. Afterwards, participants rate how highly they regard each of those opinions. Everyone's opinions are taken into account and the most highly rated ones are then circulated again for further voting (further rounds). At the end of the process agreement or consensus on a topic can be achieved. The Delphi consensus is an example of a method used to achieve this. (See Delphi Study)

Consort Statement: A structure used for reporting randomised clinical trials in academic journals. It enables readers to understand a trial's design, how it was done, how the data was analysed; and the meaning and usefulness of its results. Extensions of the CONSORT Statement have been developed for other types of study designs, interventions and data.

Constant Comparative Method: The constant comparative method is a process in qualitative research in which any newly collected data is compared with previous data collected. This is a continuous on-going procedure, because theories (i.e. ideas) are formed, developed, confirmed, or even discounted as a result of any new data that emerges from the study.

Construct: An idea or theory

Consultation (in terms of User Involvement) :Consultation involves asking members of the public for their views about research, and then using those views to inform how the research is

done This consultation can be about any aspect of the research process – from identifying topics for research, through to thinking about the implications of the research findings.

Consultation Modelling: This is a type of research method which investigates how many people visit a family doctor, for what problems, what are the factors that influence whether or not somebody will go to the doctor, and what the result of visiting the doctor is. For example do all people who go to see a doctor have less pain than people who do not go to see a doctor?

Consultation with a General Practitioner (GP): A consultation with a general practitioner is a visit to the family doctor.

Contextualise: Contextualise means to think about a word or event in terms of the general situation that it relates to, and which helps it to be understood.

Contraindications: Having a condition which makes a particular treatment or procedure potentially inadvisable. Contraindications often highlight the balance of risk versus benefit of a particular treatment or procedure.

Controlled Trial: This compares two groups of people. An experimental group who receive the new treatment and a control group who receive the usual or a placebo (i.e. dummy) treatment. (See Placebo)

Core Treatment: The basic or most important treatment.

Correlation Coefficient: A statistical term that describes how much one set of data is linked to another set data. Correlation coefficients generally take values between -1 and $+1$.

Corticosteroids: Corticosteroids, more often known as steroids, are an anti-inflammatory medicine prescribed for a wide range of conditions. (See Anti-inflammatory Drugs)

Cortisol: Cortisol is a hormone made in the adrenal glands, which are located on top of the kidneys.

Cost Effectiveness: The best use of money available for medical care. Two or more ways of performing a treatment can be compared to decide which is the best value for money.

Covariates: Anything that may affect the outcome of a clinical trial that is not part of the main experiment as it has been set up.

Cox – 2 selective inhibitor: This is a form of medication that directly targets COX-2, a substance in the body responsible for causing inflammation and pain. (See Anti-inflammatory Drugs)

Criteria: A standard by which something may be judged or decided.

Crystal Disease: A disease that occurs in and around your joints and can sometimes cause sudden (acute) attacks of painful inflammation. The main crystals that cause problems are calcium pyrophosphate (CPP) crystals and apatite crystals, and the problems they cause are referred to collectively as calcium crystal diseases.

D:

Data: Information collected during research. It can be in the form of numbers (for what is called quantitative research) or words (for qualitative research).

Data Capture in Practice: This refers to information that is collected in general practice. For example, a GP might record when he treats someone for back pain. (See Read Codes)

Data Custodian: A person that controls access to the information stored in a database but does not personally own or create the data.

Data Saturation: Normally used in qualitative research, the point at which including more participants is unlikely to generate any new themes. At this point, data collection can stop (i.e. no more interviews are done).

Delphi Study: This is a type of consensus study that uses several rounds of voting on topics to reach agreement on the most highly rated and important items. (See Consensus study)

Demographic Factors: Description of a group within a society, age, gender, location, etc.

Dependent Variable: A term used in statistics. When one variable (i.e. a factor, trait, or condition) is believed to influence another variable, the latter is called the dependent variable. (See Variable)

Design: The specific way a research study is done (e.g. a randomised controlled trial or a postal survey)

Diaries: A daily personal record of events, experiences and observations.

Diclofenac: A nonsteroidal anti-inflammatory drug (NSAID) taken or applied to reduce inflammation and pain in certain conditions. It is supplied as or contained in medications under a variety of trade names. (See Anti-inflammatory Drugs)

Discriminant Validity: A statistical term to describe the extent to which scores on a test are different with scores from other tests that are not designed to measure the same thing. For example

Dissemination: Communicating the findings of a research study to a wide range of people who might find it interesting. This can be done through producing reports, publishing articles in journals, issuing press releases, giving talks and presenting scientific posters at conferences.

Distribution: The way in which something (e.g. a health condition) is spread among a group of patients or over an area

Domains: In general, a domain is an area of knowledge or interest.

Dosing Regime: A formalised schedule by which drugs are administered, including the amount of drug, the number of doses per time period and the time between doses.

E:

Education/training outcomes: These are what happen after a person has been on a training event. So, for example, if a physiotherapist has been on a course about how to advise people to exercise for their knee pain, when they get back to their usual clinic, do they carry on advising people in the way they have just been taught.

Efficacious: Means effective. (See Controlled Trial)

Efficacy: The ability of a treatment or therapy to work as intended, under ideal and controlled circumstances (for example, in a laboratory) (nb. this is different from *effectiveness*, which is the ability of a treatment or therapy to work under 'real world' conditions).

Embryonic: Early stages.

Epidemiology: The study of how often health care problems occur in different groups of people and why.

Episodic: Composed of a series of episodes (or events).

EQ-5D™: A health questionnaire. Used in wide range of health conditions and treatments, the EQ-5D health questionnaire provides a simple description of a person's health status.

Ethics: These are a set of principles that guide researchers who are carrying out research with people. Ethical principles are designed to protect the safety, dignity, human rights, and wellbeing of the people taking part. They include the requirement to ask each individual to give their informed consent to take part in a research study.

Ethics Committee: The job of an ethics committee is to make sure that research carried out respects the safety, dignity, human rights, and wellbeing of the people who take part. Ethics committee approval is needed for health and social care research. Ethics committee members include researchers, health care professionals as well as lay people/members of the public.

Evaluation: This involves finding out whether an intervention (for example a health care treatment, service, project or programme) is achieving its aims. A project can be evaluated as it goes along or right at the end. It can explore how well the project is being carried out as well as its impact. The results of evaluations can help with decision making and planning. (See Intervention)

Evidence Based Guidelines: Evidence-based guidelines are designed to summarise the evidence available to address a specific question regarding a medical condition. 10

Evidence Based Health Care: The practice of medicine in which the physician uses methods of diagnosis and treatment based on the best available current research, their clinical expertise, and the needs and preferences of the patient.

Experimental Research: This type of research allows researchers to explore cause and effect. For example, whether a new type of drug is effective in reducing certain symptoms (e.g. pain) of a disease.

Expert: A person with a high degree of skill in or knowledge of a certain subject.

Expert Meeting: An expert meeting is a meeting that brings together people who have knowledge of the topic under discussion. Experts can be health care professionals (like consultants, nurses, physiotherapists), patients or researchers.

F:

Facilitators: People who give assistance to help make people do tasks or take part in activities.

Factor: A circumstance or fact that may influence a research finding.

First Line Agents: Drugs considered to be the first choice to treat a specific condition.

First Line Medication: For some conditions e.g. OA, there are guidelines for the order in which patients can be offered pain relieving medication, starting with less toxic medications with fewer side effects e.g. paracetamol. If these first line medications are found to be effective for that patient, there is no need to use potentially more harmful and more potent medication. If first line medications are found to be ineffective then the patient can discuss the benefits and risks of using other options with their health care professional.

Fixed Effects: (See Mixed Model)

Focus Group: A focus group is a small group of people brought together to talk about a particular subject. The purpose is to find out how people feel or think about an issue, or to come up with possible solutions to problems. This method is used particularly within qualitative research.

Forum: A meeting or presentation involving open discussion among experts and lay people.

G:

GCP Standards: GCP means Good Clinical Practice. They are a set of internationally recognised ethical and scientific quality standards which must be observed for designing, conducting, recording and reporting clinical trials that involve the human participants. Carrying out this good practice provides assurance that the rights, safety and well-being of human participants in the study are protected, and that the results of the clinical trials are accurate and can be trusted.

Generalisability: The extent to which the findings of a clinical trial can be reliably extrapolated from the subjects who participated in the trial to a broader patient population and a broader range of clinical settings.

Generalisability of Results: How much the results or findings can be transferred to situations or people other than those originally studied.

Generalisable: When the results of a study are generalisable it means that they are relevant to groups of people or patients other than the particular group that the study was carried out in. A study carried out in one region of the UK might be generalisable to the whole UK population.

Generalised Linear Modelling: Statistical term that refers to a way that data is analysed

Goodness of Fit: The goodness of fit of a statistical model describes how well it fits a set of observations. Measures of goodness of fit typically summarise the difference between what actually happened and what was expected to happen (as predicted by the statistical model).

Gout: Gout is a form of acute arthritis that causes severe pain and swelling in the joints. It most commonly affects the big toe, but may also affect the heel, ankle, hand, wrist, elbow or back. It affects the spine often enough to be a factor in back pain. Gout usually comes on suddenly, goes away after 5-10 days, and can keep recurring.

GP Research Champions: A local general practitioner (family doctor) who promotes research in general practice.

Grant: A grant is money given to researchers by funding organisations (i.e. governments, health organisations, charities) to enable them to carry out a piece of research. In order to get research studies funded, researchers have to write a research proposal and receive positive peer review (i.e. feedback from other researchers and members of the public selected by the funding organisation).

H:

Health Economics: Health economics is a type of research method that allows researchers to study the cost of treatments and benefits of treatments to the NHS and patients.

Health Policy: Health policy can be defined as the decisions, plans, and actions that are undertaken to achieve specific health care goals within a society.

Health Practitioner: A person who is qualified to work in health settings (e.g. physiotherapist or occupational therapist).

Heterogeneous: Having widely different or diverse characteristics. For example, the research study included two groups, a heterogeneous group of healthy patients under 50 years old and a homogeneous group of male patients all with arthritis, aged between 50 and 60 years old. (See Homogeneous)

Hierarchy: A group that is organised and divided into different levels according to their importance or status.

Holistic: Considering the patient as a whole and addressing the social, emotional and spiritual needs of the patient as well as their physical treatment.

Homogeneous: Things of the same type/similar or of same nature.

Hyperglycaemia: Sometimes spelt as 'Hyperglycemia' – means having high blood sugar (not to be confused with hypoglycaemia).

Hypertension: Having high blood pressure.

Hypoglycaemia: Having an unusually low level of glucose circulating in the blood. Sometimes called low blood sugar.

Hypothesis: A statement created by researchers when they speculate upon the outcome of a research project or experiment. A hypothesis should govern the design of the research and the analysis of data. So if we do this, then we expect the following to happen.

I:

Illness Perception Questionnaire: This questionnaire measures an individual's beliefs and feelings about their illness.

IMP Preparation: How the study drug (investigational medicinal product or IMP) is made.

Impact on Practice: Research can have an impact on practice, if the way that practice is managed changes because of the results of the research.

Implementation: If the results of research are taken up in health care settings they have been implemented in practice.

Inception Stage: An act, process, or instance of beginning.

Incremental Analysis: Incremental analysis is a technique used to assess the impact of small changes.

Increments: A series of small, often regular or planned increases to the amount or size of something (e.g. drug dosage or exercise time).

Individualisation: Tailoring a treatment to focus on a set of symptoms in an individual.

Indomethacin: A drug used to relieve pain, fever, and inflammation, especially from arthritis.

Ineffective Treatments: Treatments that are shown not to work as intended. 13

Inflammation: A reaction that produces redness, warmth, swelling, and pain as a result of infection, irritation, or injury. Inflammation can be external or internal.

Inflammatory Arthritis: Inflammatory arthritis is a term used to describe a group of conditions which affect your immune system. This means that your body's defence system starts attacking your own tissues instead of germs, viruses and other foreign substances. This can cause pain, stiffness and joint damage. They're also known as autoimmune diseases. The three most common forms of inflammatory arthritis are rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis. (See Systemic Diseases)

Informed Consent: The process of agreeing to take part in a study based on access to all relevant and easily understood information about what participation means, in particular in terms of the potential harms and benefits to the people who take part.

Interface: A point where two systems, subjects or organisations, etc. meet and interact, connect and work together.

Internship: A period of time, often for a year, following the close of a period of formal education during which a graduate gains practical experience.

Intervention: Something that aims to make a change and is tested through research. For example giving a drug, providing a service or giving people information and training are all described as interventions.

Interview: In research this is a conversation between two or more people, where a researcher asks questions to obtain information from the person (or people) being interviewed. Interviews can be carried out in person (face to face) or over the phone.

Investigator Site File: The Investigator Site File is a file which contains the essential and required documents necessary for the research investigator and the research team.

Involvement: Involvement in research refers to active involvement between people who use services, carers and researchers, rather than the use of people as participants in research (or as research subjects). Many people describe involvement as doing research with or by people who use services rather than to, about or for them.

J:

Jenkins Sleep Questionnaire: A questionnaire used to measure sleep problems.

Joint Aspiration: Also known as Arthrocentesis – Is a clinical procedure to collect synovial fluid from a joint capsule. The aspiration of a joint and subsequent analysis of the synovial fluid is a critical component in diagnosing arthritis.

Joint Capsule: A joint capsule is a piece of tissue that surrounds a synovial joint. Its purpose is to hold the synovial fluid of the joint in place, as well as to provide an envelope for the entire joint. (See Synovial Fluid)

Journal: A journal is a regular publication in which researchers formally report the results of their research to people who share a similar interest or experience. Each journal usually specialises in one particular topic area. Examples are The British Medical Journal [BMJ], British Journal of Social Work and The Lancet.

L:

Lay Person: The term 'lay' means non-professional. In research it refers to the people who are neither employed academic researchers nor employed health or social care professionals.

Likert Scale: A series of multiple-choice answers arranged in an ordered line used to respond to a question. They are often used in questionnaires to ask someone how strongly they agree or feel about something. For example, strongly agree; agree; undecided; disagree, strongly disagree.

Linkages between different studies: A study may be relevant to another study. If so then researchers make links between studies to share methods and results and to develop ideas for future research.

Longitudinal: A scientific study conducted over a long period of time with data collected from participants at more than one point in time during the study.

Long-term Condition: A state of health, disease or physical condition that a patient has had, or will have for a long period of time.

M:

Mapping: A researcher may map the results of their study with another study. This means working out what the similarities or differences are in terms of the methods, findings and conclusions. Researchers may also map research against health policy. This means that they find out where the research is relevant and to which policy documents.

Masters Degree: A higher academic degree given by universities to students who complete at least one year of study beyond the bachelor's or undergraduate degree (e.g. a programme of study lasting one to four years - MSc MA)

Mean: The mean is the average of a set of numbers. To calculate, (1) add up all the numbers, (2) then divide by how many numbers there are. Example, (1) $2 + 7 + 9 = 18$. (2) Divide by how many numbers (i.e. we added 3 numbers). Answer = 6 (Also known as a mean score)

Mean Score: A statistical term to describe the average value of a variable.

MedDRA: Medical Dictionary for Regulatory Activities is a respected international medical terminology dictionary used by regulatory authorities in the pharmaceutical industry during the regulatory process.

Members of the public: This term covers

- ☑ patients and potential patients
- ☑ people who use health and social care services
- ☑ informal unpaid carers
- ☑ parents and guardians
- ☑ disabled people
- ☑ members of the public who are potential recipients of health promotion programmes, public health programmes and social service interventions
- ☑ organisations that represent people who use services.

Metatarsal Bones: Metatarsals are the five long bones in the middle of the foot which connect the ankle bones to those of the toes.

Metatarsophalangeal: The metatarsophalangeal articulations are the joints between the metatarsal middle bones of the foot and the toes. (See Proximal Phalanges)

Methodology: This describes how research is done – so it will cover how information is collected and analysed as well as why a particular method has been chosen.

Methods: These are the ways researchers collect and analyse information. These include interviews, questionnaires, diaries, clinical trials, experiments and watching people's behaviour. It also includes the way that data is analysed.

Michies Theoretical Domains Framework: Named after Professor Susan Michie, a way of explaining how the behaviour of health care professionals changes when implementing evidence-based practice. (See Evidence Based Health Care)

Mixed Model: A mixed model is a statistical technique to examine the things that that might affect the outcome of an experiment. It includes both *fixed effects* (i.e. things that have not changed, e.g. gender (male or female), or things the researcher directly controls or changes, e.g. drug dosage) and *random effects* (things you cannot control in an experiment and might be random).

Modelling: Modelling is a type of statistical analysis that can identify all the important factors for example that can help to contribute to deciding best care. It is one method of deciding the best approach to treatment and uses data collected from participants within studies.

Musculoskeletal Interface Clinics: These provide a Musculoskeletal Interface Service. This is a highly specialist service of doctors, nurses and physiotherapists who deal with musculoskeletal conditions where the diagnosis is unclear or requires treatment in primary care. The Musculoskeletal Service (MIS) is a "one-stop-shop" for patients with musculoskeletal problems. (See Interface)

N:

N- Vivo Qualitative Data Management Software: Qualitative research software like NVivo, helps people to manage, shape and make sense of unstructured information (e.g. like an interview discussion). It provides a workspace and tools to enable you to easily work through information, grouping it into themes and sub themes.

Naproxen: A non-steroidal anti-inflammatory drug (NSAID) commonly used for the treatment of a wide variety of pain, fever, inflammations or stiffness.

Nested Study: A study which recruits people from a population whose characteristics are known because they are already the participants of an existing larger study (a cohort study or a large randomised control trial (RCT)). (See Cohort, Randomisation and Control Trial)

Non – Pharmacological Treatments: Ways to decrease pain or treat illnesses in addition to, or without medicine.

Non Responders: Study participants that do not complete one or more follow-up questionnaires.

O:

Observational Data: Data collected through observation.

Observational Study: Studies which attempt to understand the cause and effect of relationships. The researcher does not influence the population in any way or attempt to intervene in the study but observes the situation e.g. patient appointment within a consultant's clinic.

Opiates: A drug (as morphine or codeine) containing or derived from opium and tending to induce sleep and alleviate pain.

Optimal Care: Most favourable or desirable form of care.

Optimise: Get the most out of – the most efficient use of resources available.

Orebro Musculoskeletal Pain Screening Questionnaire: A 25-item questionnaire used to identify people at risk of developing long-term disability and failure to return to work following a muscle or joint injury.

Osteoporosis: A progressive bone disease that is characterised by a loss of bone mass and density which can lead to an increased risk of fracture.

Outcome: A planned measurement described in the protocol that is used to determine the effect of interventions on participants in a clinical trial. (See Protocol)

Outcome Strategy: A measure of the quality of medical care, the standard against which the end result of the intervention is assessed.

Outpatient Clinic: The term outpatient clinic can refer to a number of different medical facilities. These can have highly specialised types of care, or they may offer general care, like urgent facilities. Such clinics may be designated “outpatient” because they are attached to hospitals but do not serve patients who need to stay in hospital overnight. However, an outpatient clinic does not have to share facilities with a hospital, and some are not located on hospital campuses.

P:

Pain Intensity Numeric Rating Scale: Commonly used questionnaires which ask people to rate their level of pain, usually on a scale from 0 (meaning absence of pain) to 10 (representing the most intense pain possible).

Pain Self Efficacy Questionnaire: A 10-item questionnaire which measures the confidence of people with persistent pain to carry out activities whilst in pain. 18

Palliative Care: Care for the terminally ill and their families.

Paradigm: A set of assumptions, concepts, values and practices that constitutes a certain way of viewing things. A paradigm could be a pattern of thought.

Parallel Study: A type of clinical study where two treatments (e.g. drug A and drug B) are tested. One group patients receives drug A only, while another group of patients receives drug B only.

Participant: Someone who takes part in a research study. Can also be referred to as a research subject.

Pathology: The scientific study of the nature of disease and its causes, processes, development and consequences.

Patient Reported Outcomes: A patient reported outcome measure is a questionnaire that asks the person to report how they feel on a particular topic. It may ask for example how much pain a person has felt in the last 24 hours and ask them to rate it from none, mild, moderate, severe or extreme.

Peer Reviewing: This is where a research proposal or a report of research like a journal article is read and commented on by people with similar interests and expertise to those who wrote the proposal or report. Peer reviewers might be members of the public, researchers, statisticians or other health professionals. Peer review helps to check the quality of a report or research proposal. It acts as a useful quality control activity. (See Proposal)

Performance Measures: A system of measuring the way in which something is carried out or how it functions in order to compare it to a set standard.

Peripheral: Situated at or near the periphery i.e. boundary or surrounding

Pharmacovigilance: (abbreviated PV or PhV), also known as Drug Safety, is the collection, detection, assessment, monitoring, and prevention of adverse effects (i.e. side effects) of medicines.

Physical Activity Adherence: A study might test whether one activity programme is better than another in reducing pain. In this type of study it is important that the people taking part in the different types of activity complete the plan as it was intended. So if the plan was to exercise for 3 hours a week for 6 weeks, did the person do this? If they did, they have adhered to the plan.

Physiological: How a treatment or drug influences how the body systems or organs work.

Pilot Study: A pilot study is a small study set out as a rehearsal or practice for a larger study. The aim is to check whether or not the methods will work before committing to the main study, and to spot any mistakes in the design or management of the study.

Placebo: A fake or dummy treatment that is designed to be harmless and have no effect. It allows researchers to test for the placebo effect. By comparing people's responses to the placebo and to the treatment being tested, researchers can tell whether the treatment is having any real benefit.

Placebo Effect: This is a psychological response where people feel better because they have received some treatment and not because the treatment has a specific effect on their condition.

Population: This term can refer to the participants in a healthcare study; or it can also refer to a general population of people.

Portfolio: A listing of research topics.

Postal Survey: A postal survey in research will involve a questionnaire being mailed out to individuals and includes a pre-paid return envelope.

Practice Level Outcomes: This is information that is collected in general practice as part of General Practitioner care, for example the number of patients taking a particular drug, the

number of patients referred to physiotherapy. One practice can be compared with another, or they can be compared against a standard of best care.

Pragmatic Trial: Pragmatic trials are designed to evaluate the effectiveness of interventions in real-life routine practice conditions.

Pragmatism: Practical matter of fact way of approaching or assessing situations or of solving problems.

Predicate: To base or establish (a statement or action) e.g. I predicated my argument on the facts.

Predictors: Factors that are identified in an individual or groups of people that helps to understand what might happen to that person or group in the future.

Predictive Performance: *The accuracy of a statistical model to predict the correct outcomes as expected*

Prednisolone: A steroid drug which may be used to treat a variety of inflammatory and auto-immune conditions.

Prescriptive: For example, a research question or method is outlined and already defined.

Prevalence: The number of cases of a specific disease present in a given population at a certain time.

Primary Analysis: The first or original analysis of data collected in a research study.

Primary Care: The medical care received on first contact with the medical system, for example – GPs, nurses, physiotherapists and any other forms of community healthcare.

Primary Disease: A disease arising spontaneously and not associated with or caused by a previous disease or injury.

Primary Endpoint: The main result that is measured at the end of a study to see if a given treatment worked. What the primary endpoint will be is decided before the study begins. Also known as Primary Objective.

Primary Outcome Measure: A measurement used to show whether the medication or intervention has made any difference and if so, by how much. (See Intervention)

Principal Investigator: The first or original analysis of data collected in a research study.

Prognosis: Factors that are identified in an individual with a particular disease that helps to understand what might happen to that person in the future.

Prognostic Factors: A situation or condition, or a characteristic of a patient, that can be used to estimate the chance of recovery from a disease or the chance of the disease recurring (coming back).

PROMIS Pain Interference Scale: A questionnaire which measures how much pain interferes with different aspects of one's life, including social, cognitive, emotional, physical, and recreational activities.

Prospective Observational Cohort: A study which follows over time a group of similar individuals (cohorts) who differ with respect to certain characteristics under study. These studies find out how characteristics of individuals affect rates of a certain outcome.

Proposal: This is a written document that outlines the plan for the research. It will also cover the background to the study, aim of the research, methods, who will be involved and how many people will be involved, the time scale and the cost.

Protocol: A protocol describes in great detail what the researchers will do during the research. A protocol will be submitted to the ethics committee for approval.

Proximal Phalanges: Proximal phalanges are the bones in the fingers and toes.

Psychological: Relating to or arising from the mind or emotions.

Psychometrics: The science of measuring aspects of psychology such as knowledge, abilities

Psychosocial: The term psychosocial refers to the psychological and social factors that influence mental health.

Purines: A natural substance found in most foods which can trigger attacks of gout in sufferers.

Purposive Sampling: This is often used in qualitative research where a group of people are invited to be interviewed on the basis of their characteristics. For example, people who have consulted a general practitioner, or live in a deprived area.

P-value: A measure of the probability or likelihood that a given effect or event will take place by chance. The smaller the P-value, the more likely that the intervention is responsible for an observed effect.

Q:

Qualitative: Qualitative research is used to explore and understand people's beliefs, experiences, attitudes or behaviours. It asks questions about how and why. Qualitative research might ask questions about why people self-manage for knee pain. It won't ask how many people self-manage their knee pain. It does not collect data in the form of numbers. Qualitative researchers use methods like focus groups and interviews (telephone and face to face interviews).

Quality Adjusted Life Years (QALY): A way to measure the burden of a disease. It includes both quality and quantity of life. The QALY is based on the number of years of life that would be

added by the intervention (e.g. drug or treatment). It is often used in assessing the value for money of a medical intervention.

Quality Markers / Indicators: These are defined standards to measure the process of care, for example, did the patient consulting their GP with OA get offered advice on exercise and physical activity? These are often measured in a health care setting or organisation e.g. with practice level outcomes (see Practice level outcomes).

Quantitative: In quantitative research, researchers collect data in the form of numbers. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year, or whether a new drug gives more effective pain relief than the drugs that are usually used. Quantitative researchers use methods like surveys and clinical trials.

Questionnaires: A series of questions and other prompts for the purpose of gathering information from an individual. (See Surveys)

R:

Randomisation: Assigning participants in a research study to different groups without taking any similarities or differences between them into account. For example participants in a study could have their names randomly picked out of a hat to see which group they will be in. Randomisation minimises the differences among groups by equally sharing people with particular characteristics among all of the groups.

Randomised, multi-centre, single-blind, active comparator, pragmatic clinical trial: This can be broken down to

- ☐ *Randomised clinical trial* - A study where patients are randomly allocated to a treatment
- ☐ *Multi-centre study* - Study takes place at more than one site e.g. different GP practices recruit patients
- ☐ *Single-blind* – When patients do not know what treatment they are receiving in the study.
- ☐ *Active comparator* - The drugs that are being compared in the study both treat the condition that is being studied.
- ☐ *Pragmatic study* - a study looking at how well a treatment works in the real world.

Read Codes: A coded list of standard clinical terms that doctors use to keep records. They record things such as investigations (blood tests, scans etc.) diagnoses (descriptions of the conditions suffered), operations, drugs and therapies.

Red Flags: Red flags are signs of possible serious underlying conditions requiring further medical intervention.

Rehabilitation: Rehabilitation is a treatment or treatments designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible.

Research: The term research means different things to different people, but it is essentially about finding out new knowledge that could lead to changes to treatments policies or care. The definition given by the Department of Health is “the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods.”

Research Brief: Research Commissioners (i.e. people who say what research is needed) write a research brief. The brief describes why they want to commission a piece of research, what questions the research should address and sometimes how the research should be carried out. It might include information about when the research needs to be completed and how much money is available. Researchers then write a research proposal that explains how they will address the research brief. They will submit the proposal and hope to get a grant (money) to carry out the research.

Research Clusters: The way in which something is grouped for the purposes of research. So for example, general practices in one area may be put into one cluster and all those in the neighbouring area into another.

Research Governance: This is a process aimed at ensuring that the research is of high quality, safe and ethical. The Department of Health has a Research Governance Framework for Health and Social Care, which everyone involved in research within the NHS or Social Services must follow.

Research Methods or Techniques: The ways in which researchers conduct research. This includes how researchers collect data (i.e. Interviews, questionnaires, clinical tests) and analyse data (statistics, modelling).

Researchers: These are the people who do the research. They may do research for a living and be based in a university or hospital. Researchers may also be service users or carers.

Responder Criteria: A set of conditions (e.g. change in symptoms, need for surgery) that determines whether a treatment has been effective for an individual patient or not.

Rigorous: Meaning thorough and precise. Normally used in research when describing the quality of the methods used in the study. Rigorous research methods are consistent and comply with a set of standards.

Risk Strata Cut Points: A level of risk which is considered acceptable.

Risk Stratum: A level of risk which is determined by identifying characteristics of individuals associated with an increased chance of experiencing unwanted outcomes.

Royal College of General Practitioners Patient Group: This is a working partnership at the Royal College and brings together doctors and patients.

S:

Salient: Something which is very noticeable or relevant.

Screening: Tests performed to identify clinical issues for example - anxiety and depression in people with OA. The reason to screen is to then follow up with some intervention or healthcare to help with the issue that has been picked up. Used in research to confirm that people have certain health conditions before they are recruited into a study.

Secondary Analysis: This involves the use of existing data, collected for the purposes of a previous study, for reasons which are different from the original research; this may be a new research question or an alternative perspective on the original question.

Secondary Care: Typically care given in a hospital setting or specialist medical facility. Patients can be referred to secondary care by a primary care clinician (i.e. GP) if more specialised care, knowledge, skill or equipment is needed.

Secondary Endpoint: Results that are measured, in addition to the primary endpoint, to look at the effect of a certain treatment.

Secondary Outcome Measure: The outcome measures in a clinical trial that provide information on therapeutic effects of secondary importance, side effects or tolerability. Data on secondary outcomes are used to evaluate additional effects of the intervention not included in the primary outcome measure.

Self –Titration: When a patient adjusts the dose of a drug to achieve a given effect e.g. reduction in pain

Self-Management: Self-management has different meanings to different people (for example the Department of Health, doctors and patients). For patients, generally it means the activities and skills they use to take care of themselves. For example, people who have osteoarthritis have developed sophisticated ways of managing their joint problems without needing to visit their general practitioner.

Sensitivity Analysis: Sensitivity analysis is a way to determine what the impact of changes in things (i.e. cost of treatment) will have on the outcomes of an intervention (i.e. use of drug by GPs, patient's symptoms)

Service User: This is someone who uses or who has used health and/or social care services because of illness or disability.

SF-36: The Short Form 36 (SF-36) is a general health related quality of life questionnaire which can be used for a range of health conditions. It gives a score based on the patient's mental and physical health. The SF-36 can be used to calculate the cost-effectiveness of a health treatment. The SF-12 and SF 6D are shorter versions of the questionnaire.

SF-36 v2: Version 2 of the SF-36 questionnaire (See SF-36).

Smooth Trial: The short name of the 'Self Management in Osteoarthritis of the Hand research study'.

Social Factors: Description of a group of people within a society – their employment, skills, education and social class.

Sociodemographics: Word used to describe a group within a society. It considers a large list of demographic factors (age, gender, location, etc.) and social factors (employment, skills, education, social class).

Source Data Verification Exercise: A way to check that the information received on study paperwork is correct by looking at documents at trial sites e.g. medical records at a GP practice.

Spondylarthropathy: (also known as spondyloarthritis) A group of long term diseases of joints, including ankylosing spondylitis, Reiter's syndrome (reactive arthritis), psoriatic arthritis, and joint problems linked to inflammatory bowel disease. They usually affect the attachments between the lower back and the pelvis and areas around the joint where your ligaments and tendons attach to bone, such as at the knee, foot, or hip.

Standard Deviation: Is a number used to tell how measurements for a group are spread out from the average (mean), or expected value. A low standard deviation means that most of the numbers are very close to the average. A high standard deviation means that the numbers are spread out. (See Mean)

Standardised Effect Size: Represents the size of difference between two treatment groups.

STarT Back Screening Tool: A 9-item questionnaire designed to classify patients with low back pain into one of three subgroups for targeted primary care management.

Statistical Analysis: Statistics are a set of numbers (quantitative data) obtained through research. Statistical analysis uses a set of mathematical rules to analyse this data. For example, statistical analysis can assess whether any difference seen between two groups of people is likely to be a reliable finding or simply due to chance. 25

Statisticians: These are people who analyse quantitative (numerical) data.

Steering Group: A special group or committee that is set up to manage a study. This will include overseeing the study's aims and progress and reporting to the funder. A steering group may meet 2 or 3 times a year, or it may meet every month, depending on the study.

Steroid: One of a large group of chemical substances classified by a specific carbon structure. Steroids include drugs used to relieve swelling and inflammation, such as prednisone and cortisone; vitamin D; and some sex hormones.

Strategy: A plan of action intended to reach a specific goal

Stratified: Participants in a study may be classified or grouped into different levels. For example responders to a postal questionnaire may be stratified into age groups of 50-64yrs, 65-74yrs and 75 and over.

Stratified Randomisation: Stratified randomisation prevents imbalance between treatment groups for known factors that influence how well the treatment might work.

Subgroups/sets: When participants of a study are further divided according to factors e.g. age, sex, severity of the disease, or physical condition.

Suboptimal: Less than or below the best standard.

Survey: A survey is a way of gathering information from a sample of people who are considered to be representative of a whole general population. A survey can be undertaken by postal

questionnaire, or undertaken face to face (e.g. in research clinics), or can be undertaken using medical records.

Synovial Fluid: A clear fluid that lubricates the linings of joints and the sheaths of tendons present in many joints of the body.

Systematic(ally): Carried on by using step-by-step procedures in an efficient and methodical way.

Systematic Reviews: Systematic Reviews aim to bring together the results of all studies addressing a particular research question that has been carried out worldwide. They are used to bring the results of a number of similar trials together, to piece together and assess the quality of all the evidence. Combining the results may give a clearer picture.

Systemic Diseases: These are conditions that can affect your whole body. They can happen at any age. (See Inflammatory Arthritis).

T:

T – Test: A statistical term used to compare two groups having different average values and is used to check whether two sets of measures are essentially different.

Techniques: A way or method of doing something.

Themes: The main ideas or recurrent topics repeated throughout the study. 26

Theory: An idea or set of ideas intended to explain something. (See Hypothesis)

Time Lines: A sequence of related events arranged in chronological order – the order in which they occurred – and displayed along a line (usually drawn left to right or top to bottom). (See Chronological Order)

Tools: Usually used in research to mean a questionnaire or something used by a doctor or nurse to help care for patients (e.g. information booklet).

Triaged: This is the process of determining the priority of patients' treatments based on the severity of their condition. This rations patient treatment efficiently when resources are insufficient for all to be treated immediately.

Two Arm Parallel Study: A study that tests a treatment on two separate groups of participants.

U:

Undergraduate: A person studying in a university for a first degree.

Unsafe Treatments: Treatments are unsafe for use on humans.

Urate Lowering Therapy: A therapy for lowering uric acid levels in the treatment of Gout. Urate lowering therapy can be very effective for reducing flares of gout, thereby preventing on-going joint damage and deformity.

Uric Acid: Uric acid is a chemical created when the body breaks down substances called purines. Purines are found in some foods and drinks. Most uric acid dissolves in blood and travels to the kidneys. From there, it passes out in urine. If your body produces too much uric acid or doesn't remove enough of it, you can get sick. A high level of uric acid in the blood is called hyperuricemia.

V:

Variable: Any factor that can be controlled, changed, or measured in a research study.

Verbatim: Using exactly the same words as were used originally to create a precise record of a conversation or proceedings.

Verification: The process of establishing the truth, accuracy, or validity of something e.g. the verification of official documents.

Vignettes: Vignettes are short scenarios or stories in written or pictorial form which patients can comment on in both quantitative and qualitative research.

Viscous: Having a thick, sticky consistency between solid and liquid.

W:

Weighted Kappa: The Kappa coefficient or Weighted Kappa are statistical terms used in the analysis of research data. Kappa is defined in weighted or un-weighted forms and used to assess how reliable (i.e. trustworthy) the data is.

Explanation of Abbreviations (Acronyms)

A:

A&E: Accident and Emergency

AE: Adverse Events

AHP: Allied Health Professionals

AHSN: Academic Health Sciences Network

APEX: Acupuncture in Knee Pain Trial

ARC: Arthritis Research Campaign

ARUK: Arthritis Research UK

ASES: Arthritis Self – Efficacy Scale

ATLAS: Assessment and Treatment of Leg pain Associated with the Spine

B:

BEEP: Benefits of Effective Exercise for Knee Pain

BSR: British Society of Rheumatology

BHPR: British Health Professionals in Rheumatology

BNF: British National Formulary

C:

CAT: Critically Appraised Topic

CBT: Cognitive Behaviour Therapy

CCG: Clinical Commissioning Group

CI: Chief Investigator

CiPCA: Consultation in Primary Care Archive

CKS: Clinical Knowledge Summaries

CLAHRC: Collaboration for Leadership in Applied Health Research & Care

CLAHRC-WM: Collaboration for Leadership in Applied Health Research & Care - West Midlands

CLRN / CRN: Previously Clinical Local Research Network. Now known as the Clinical Research Network.

CPD: **Continuous Professional** Development

CQUIN: Care Quality Indicator

CRF: Case Report Forms

CSP: Chartered Society of Physiotherapists

CSU: Commissioning Support Units

CtE: Commissioning through Evaluation

CTIMP: Clinical Trial of an Investigational Medicinal Product

CTU: Clinical Trials Unit

CVS: Contract Variations

D:

DH/DoH: Department of Health

DMC: Data Monitoring Committee

DMEC: Data Monitoring and Ethics Committee

DNA: Did Not Attend

E :

EULAR: European League against Rheumatism

G:

GP: General Practitioner

GPAQ: General Practise Assessment Questionnaires

H:

HCP: Health Care Practitioner

HEE: Health Education England

HEI: Higher Education Institutes

HRA: Health Research Authority

HTA: Health Technology Assessment 30

I:

ICC: Intracluster Correlation Coefficient

ICMJE: International Committee of Medical Journals Editions

IMPs: Investigational Medicinal Products.

IMPACT BACK: Implementation Study to Improve Patient Care through Targeted Treatment for Back Pain

IPR: Intellectual Property Rights

ITT: Intention to Treat

K :

KAPS: Keele Aches and Pains Study

L:

LBD: Lower Back Pain

M:

MCID: Minimum Clinical Importance Difference

MDC: Minimal Data Collection

MHRA: Medicines and Healthcare Products Regulatory Agency

MOSAIC: Management of Osteoarthritis in Consultations

MOAC1: Model OA Consultation with the GP, the first contact with a health professional in the general practice

MOAC2: Model OA Consultation with the practice nurse, the second contact with a health professional in the general practice

MRC: Medical Research Council

MRI: Magnetic Resonance Image

N:

NAPP: National Association of Public Participation

NCB: National Commissioning Board

NHS: National Health Service

NICE: National Institute for Clinical Excellence 31

NIHR: National Institute of Health Research

NSAIDs: Non-steroidal anti Inflammatory drugs

NSC: North Staffordshire Consortium

NSCCG: North Staffordshire Clinical Commissioning Group

NORSTOP: North Staffordshire Arthritis Project

O:

OA: Osteoarthritis

OARSI: The Osteoarthritis Research Society International

OMERACT: Outcome Measures in Rheumatology

P:

PCC: Primary Care Centre

PCR: Primary Care Rheumatology Society

PCRN: Primary Care Research Network

PCR WMN: Primary Care Research West Midlands North

PCS: Physical Component Summary

PCT: Primary Care Trust

PhD: Doctor of Philosophy

PHE: Public Health England

PI: Principal Investigator

PMC: PubMed Central

PP: Per Protocol

PPI: Patient and Public Involvement

PROG-RESS: Prognosis in Research

PROMIS: Pain Interference Scale

PSEQ: Pain Self – Efficacy Questionnaire

QALY: Quality Adjusted Life Year

QiPP: Quality Innovation Productivity & Prevention

QP: Quality and Productivity Indicator

QOF: Quality Outcome Framework

R:

RCGP: Royal College of General Practice

RCP: Royal College of Physicians

REF: Research Excellence Framework

RCT: Random Controlled Trial

RDS: Research Design Service

REC: Research Ethics Committee

RfPB: Research for Patient Benefit

RUG: Research Users Group

S:

SAE: Serious Adverse Events

SHAR: School of Health & Rehabilitation

SLA: Service Level Agreement

SOP: Standard Operating Procedure

SMooth: Self-Management in Osteoarthritis of the Hand

SmPc or SPC: Summary of Product Characteristics

SSOTP: Staffordshire and Stoke on Trent Partnership Trust

STarT Back: Screening and Targeted Treatment for Back Pain

STEMS: STepping up the Evidence for Musculoskeletal Services

SUSAR: Suspected Unexpected Serious Adverse Reaction

SWAP: Study of Work and Pain

T:

TDF: Theoretical Domains Framework

TSC: Trial Steering Committee

U:

UHNM: University Hospitals of North Midlands NHS Trust.

UKPMC: United Kingdom PubMed Central

W:

WHO: World Health Organisation

WMAHSN: West Midlands Academic Health Science Network

WMN PCR: West Midlands North Primary Care Research Network

WTP: Willingness to Pay