JARGON BUSTER

Centre for Musculoskeletal Research
University of Manchester

OUTLINE JARGON BUSTER

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STUDY DESIGN AND RESEARCH RELATED JARGON

A

Abstract - this is a brief summary of a research study and its results. It tells why the study was done, how the researchers went about it and what they found.

Adherence (Compliance) - adherence to treatment means sticking to the treatment as prescribed by a health care professional.

Adverse events (Side effect) - adverse events are undesired effects that may or may not be related to a treatment. For example, if you someone is given a drug to treat an illness and that person becomes sick (e.g. dizziness, stomach ache or a rash), this would be described as an adverse event. Clinical trials will often look at both short- and long-term adverse events related to a treatment.

Advisory group (steering group) - many research projects have an advisory group (or steering group). The group helps to develop, support, advise and monitor the project. The group often includes people who use services, carers, researchers and other health and social care professionals, who can provide relevant advice.

Analysis (data analysis) - data analysis involves examining and processing research data in order to answer the questions that the project is trying to address. It involves identifying patterns and drawing out the main themes, and is often done with specialist computer software.

Audit -

B

Baseline – this is the initial assessment at the start of a research project or clinical trial.

Basic research - basic research aims to improve knowledge and understanding, rather than finding a solution to a practical problem. It usually involves work in a laboratory – for example to find a gene linked to a disease, or to understand which cells are involved in a disease.

Bias - in research, the term 'bias' is used when a particular design or analysis is likely to favour a particular outcome. In a clinical trial, if one treatment is always given to participants who have a more severe form of a disease, then this treatment will appear worse than others. Bias can also happen if a researcher knows about the treatment a participant is receiving, and this interferes with the researcher's ability to be impartial.

Blinded trial - the principle that if you don't know what treatment you are on, you cannot influence the results. Single blind means that only the patient doesn't know whether he or she gets the real drug or placebo. Double blind means that neither the patient nor the clinician (doctor, nurse or researcher) knows what the patient receives.

C

Case study - research based on one or a few patients. Case studies may be very detailed and are a good way of finding out about rare conditions or illnesses.

Classification and diagnostic criteria - illnesses, or diseases, cause patients to have different symptoms and signs are often associated with abnormal test results. Not all patients have exactly the same pattern of complaints. Classification and diagnosis criteria allow doctors and researchers to classify the various types of a disease (eg rheumatoid arthritis) they treat. Disease classification can also be useful to recruit patients to a trial, and be sure that the patients in the trial have similarly severe disease. Where a patient has a pre-defined set of features, which relate to a particular disease, he or she may be said to fulfil the diagnostic criteria of the disease.

Clinical trial (trial) - clinical trials are research studies involving people who use services, 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.

Clinical research - clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes comparing them with healthy people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records, or from questionnaires completed by people with the disease.

Cohort study - a study design concerned with observing events involving a particular group of people over time (such as a how group of patients using a certain treatment progress over time) in order to provide information about the outcomes, which is useful for identifying longer-term strategies, and treatments that are effective.

Collaboration - collaboration involves active, on-going partnership with other researchers or members of the public in the research process. For example, to design, undertake and/or disseminate the results of a research project.

Commissioner - a commissioner is the person (or organisation) who asks for a piece of research to be carried out.

Commissioning board / commissioning panel - a commissioning board is a group of people who oversee the commissioning process. It is made up of research funders, researchers, health and/or social care professionals and often includes people who use services and carers.

Composite measure – a measurement instrument that combines different aspects of the disease into a single numerical value. For example, the 28-joint Disease Activity Score (DAS28) is a measure based on the number of swollen and tender joints out of 28 joints, the visual analogue scale for general well-being completed by the patients and CRP or ESR blood values (measure of inflammation).

Confidentiality - during a research project, the researchers must put data protection measures into place, to ensure that all of the information collected about the participants is kept confidential. This means that the researchers must get the participants' written permission to look at their medical or social care records. It also means that any information that might identify the participants cannot be used or passed on to others, without first getting the participants' consent.

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Confounding - variables which might confuse your answer. For example, there seems to be an association between alcohol and lung cancer. But this does not mean alcohol causes lung cancer. The link is really between smoking and lung cancer – and thus we say that alcohol confounds or confuses the issue because the people who drink alcohol are more likely to smoke and therefore get lung cancer.

Construct validity – the degree to which a test measures what it claims, or purposes, to measure. How well is a measure associated with other measures.

Consultation - consultation involves asking members of the public for their views about research, and then using those views to inform decision-making. 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. Having a better understanding of people's views should lead to better decisions.

Consumer - the term consumer is used to refer collectively to:

- People who use services
- Carers
- Organisations representing consumers' interests
- Members of the public who are the potential recipients of services
- Groups asking for research to promote good health or because they believe they have been exposed to potentially harmful circumstances, products or services

Content validity - evidence from qualitative research demonstrating that the instrument measures the concept of interest (eg pain, functional disability, work productivity). Testing other measurement properties will not replace or rectify problems with content validity.

Criterion validity - the extent to which the scores of a new instrument or outcome measure are related to a known "gold standard measure" (i.e. the measure available asking about the topic). Criterion validity cannot always be measured because there is no gold standard.

Cross-over study – in a cross-over study people will receive all treatments under investigation, one treatment first and then another treatment. Comparisons are then made between how well the patients felt during the different periods. For example, if a trial is comparing the effectiveness of 2 different sorts of exercise, one group may take part in exercise A for the first part of the trial and then exercise B for the second, while the other group will start with exercise B and then A.

Cross sectional - a cross-sectional study is an observational study, in which all data needed to answer a certain research question are collected on a single occasion. Cross-sectional studies can be a useful way of getting a lot of information quickly but are not considered as powerful as prospective (or longitudinal) studies in which patients or a disease process are followed over time.

D

Data - data is the information collected through research. It can be collected using eg questionnaires, surveys, medical notes or interviews. It is usually stored on or transferred to a computer, so that it can be analysed, interpreted and then communicated to others, e.g. in manuscripts, reports, graphs or diagrams.

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Data monitoring committee (DMC) - most trials have an independent data monitoring committee that follows the progress of the trial and makes sure it is being run properly. The people on the data monitoring committee are experts in clinical trials, statistics or in the disease being studied. They are independent of the researchers running the trial. If they think that participants are experiencing serious or unexpected side effects, or if evidence has emerged that one of the treatments being compared is clearly better than the others, they can advise that a trial is stopped. **Data protection -** all personal information is protected in the UK by the Data Protection Act (1998). This means that researchers have to put in all the necessary safeguards to protect the confidentiality of the information they collect about research participants. They should explain in the patient information sheet:

- How the participants' data will be collected
- How it will be stored securely
- What it will be used for
- Who will have access to the data that identifies participants
- How long it will be kept
- How it will be disposed of securely

Delphi method – a structured method asking experts in the field to comment on statements related to the outcome of interest with an aim of achieving consensus on how to define for example disease criteria.

Dissemination - dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through:

- Producing reports
- Publishing articles in journals or newsletters
- Issuing press releases
- Giving talks at conferences

It is also important to provide feedback of the research findings to research participants.

E

Effect size – is a quantitative measure of the strength of a phenomenon.

Efficacy - the extent to which a treatment improves outcomes under the ideal circumstances, for example the maximum effect in patients who didn't experience side effects and took all prescribed drugs.

Efficiency - (a statistical measure) – the mean (average) change in the measure divided by the standard deviation (a statistical measure of spread) of the change.

Effectiveness – whether a drug or other treatment works in real life. Effectiveness studies of drugs look at whether they work when they are used the way most people take them. Effectiveness means that most people who have the disease would improve if they used the treatment.

Eligibility criteria - all trials have guidelines about who can take part. These are called 'eligibility criteria', consisting of underline inclusion criteria and exclusion criteria. For example, the eligibility criteria for a

trial looking at a certain treatment for rheumatoid arthritis might say that the only people who can take part must be over 18 but under 65 years and who have not used a specific medication for rheumatoid arthritis before.

Empowerment - This is the process by which people who use services equip themselves with the knowledge, skills and resources they need to be able to take control over decisions and resources. It often involves people building confidence in their strengths and abilities. It does not always mean people take control over all decisions or all resources.

Epidemiological study - an epidemiological study looks at how certain exposures/'risk factors' (for example cigarette smoking) or other demographic or clinical factors may affect health outcomes (for example disease activity or disability). An epidemiological study may also look at causes of a disease or investigate the association between a new treatment and the development of side effects.

Ethics - ethics are a set of principles that guide researchers who are carrying out research with people. Ethical principles are designed to protect the safety, dignity, rights and well-being of the people taking part. They include the requirement to ask each individual to give their informed consent to take part in a research project. Before a study starts a researcher needs to seek ethical approval.

Ethics committee - the job of an ethics committee is to make sure that research carried out respects the dignity, rights, safety and well-being of the people who take part. Ethics committee members include researchers and health care professionals as well as members of the public.

Evaluation - this involves assessing whether an intervention (for example a treatment, service, project, or programme) is achieving its aims. A project can be evaluated as it goes along or right at the end. An evaluation can measure how well the project is being carried out as well as its impact. The results of evaluations can help with decision-making and planning.

Evidence based - an evidence base is a collection of all the research data currently available about a health or social care topic, such as how well a treatment or a service works. This evidence is used by health and social care professionals to make decisions about the services that they provide and what care or treatment to offer people who use services.

Exclusion criteria - exclusion criteria determine who is not eligible to join a study – for example, some studies investigating a certain treatment exclude women who are pregnant, or who may become pregnant, to avoid any possible danger to the baby. Studies may also exclude people who are taking a drug that interacts with the treatment being studied. (See also eligibility criteria and inclusion criteria.)

Experimental research - this type of research allows researchers to explore cause and effect. For example, experimental research would be used to see whether a new drug is effective in reducing blood pressure. The research design will tell the researcher whether any reduction in blood pressure is definitely due to the drug.

Experts by experience - the term 'experts by experience' refers to service users and carers, who are experts through their experience of illness or disability and services.

F

Focus group - a focus group is a small group of people brought together to talk about a specific topic. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.

G

Grey literature - grey literature is material that is less formal than an article in a peer review journal or a chapter in a book – so it's not easily tracked down. It includes internal reports, committee minutes, conference papers, factsheets, newsletters and campaigning material.

H

Health economics - in some clinical trials, it can be important to compare how much different treatments or treatment plans cost, as well as how well they work. This can be particularly important when two (or more) treatments are equally effective, but where one costs much more than the other.

Health inequality - a difference in health or health status between groups of people defined by social factors such as ethnicity, gender, social class etc.

Honorary contract - honorary contracts are required by anyone who wants to carry out research or observe people in an NHS setting, but who does not already have an employment contract or a volunteer contract with the relevant NHS Trust. The contract ensures that they are covered by NHS liability insurance, and that they are contractually bound to take proper account of the NHS duty of care.

Hypothesis - a proposed mechanism that might explain a known fact or observation. A hypothesis may be tested by a well-designed research protocol. Unlike a theory it is not supported by direct evidence, rather it is the question asked in a research study.

I

Implementation - implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.

Inception cohort – all individuals assembled at a given point or entering a study based on a factor, such as where they live, with a certain disease. For example the Norfolk Arthritis Register includes patients in the Norfolk area with more than 2 swollen joints lasting for more than 4 weeks.

Incidence - the incidence of disease is defined as the number of new cases of disease occurring in a population during a defined time interval. The number is used to measure risk. High incidence may indicate an impending epidemic. Incidence is different from prevalence. (See Prevalence)

Inclusion criteria - the predefined characteristics that allow a subject to be entered for consideration for a study. For example, some trials only include people of a certain age, or at a particular stage in their illness. (See also eligibility criteria and exclusion criteria.) For example in a study of osteoarthritis, inclusion criteria might be determined as pain on most days of the previous month and definite radiographic evidence of osteoarthritis of the affected joint.

Informed consent - you cannot be entered into a study without signing a form saying that you have given your informed consent, except in extreme circumstances (for example, if you're admitted to hospital in an emergency and you're unconscious). If you sign this form, you are saying that you believe you have been given all the important facts about a trial or study, you understand them and that you have decided to take part in the trial of your own free will. Even after giving your informed consent, you are free to withdraw from the trial at any time without giving a reason and without it affecting your healthcare.

Intervention - an intervention is something that aims to make a change and is tested through research. For example, giving a drug is an intervention. Counselling and surgery are also interventions. Within the context of a clinical trial, the 'intervention arm' is the name given to the group of people receiving the new treatment or treatment plan.

Interview - in research, an interview is a conversation between two or more people, where a researcher asks questions to obtain information from the person/patient (or people) being interviewed. Interviews can be carried out in person (face-to-face) over the phone or online.

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

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. Annals of Rheumatic Diseases (ARD), Rheumatology, and The Lancet are examples of journals.

L

Lay (lay person) - the term lay means non-professional. In research, it refers to the people who are neither academic researchers nor health or social care professionals.

Lay summary - a lay summary is a brief summary of a research project or a research proposal that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included.

Longitudinal observational studies - in an observational or epidemiological study, researchers do not offer different treatments as part of the research. They study how certain 'risk factors' and disease outcomes are related.

M

Members of the public (or public) - : members of the public include:

- Patients and potential patients
- People who use health and social care services
- Informal (unpaid) carers
- Parents/guardians
- Disabled people
- Members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions
- Groups asking for research because they believe they have been exposed to potentially harmful substances or products (for example pesticides or asbestos)
- Organisations that represent people who use services.

Mentor - a mentor is a person willing to share their experience, knowledge and wisdom to help, guide and support someone who is less experienced. A person who is newly involved in research can ask for a mentor to help them adjust to their new role.

Meta-analysis - a meta-analysis involves a researcher bringing together the numerical results of all previous research which has already been published (usually randomised trials) about one particular treatment or plan. A meta-analysis can be important because it allows us to pick up small differences between treatments. By bringing together the results of all trials of a particular treatment in a meta-analysis, we can look at the experience of more participants than in a single trial. This gives a more reliable and accurate measurement of the effect of the treatment and the best way of seeing which treatments are best.

Methodological Research - methodological research in relation to clinical studies is research looking at ways to improve how trials are designed, carried out, conducted, analysed, interpreted and reported.

Methodology - the term methodology 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.

Minimal clinically important difference - a minimal clinically important (or relevant) difference (MCID) can be defined as the smallest difference in a score on an outcome measure (eg pain, quality of life) which patients perceive as beneficial. This MCID can be used as a criterion to assess if a therapy has potential beneficial effects.

Monitoring research - monitoring research involves keeping up to date with the progress of a research project. This will include ensuring that the researchers are carrying out their research according to their <u>research proposal</u> or <u>protocol</u>, that the research is keeping to time and budget and that the research is being conducted ethically.

O

Open label trials - in an open label trial, both the study participant and the doctor will know which treatment the participant receives. This is the opposite of a double-blind trial (see blinding).
Outcome - an outcome is the result in which the researcher is interested, for example the effect of treatment on a patient. Objective measures (outcomes) are independent of the opinion of the patient, e.g. radiologic joint damage (X-rays), biological blood tests (rheumatoid factor, serum levels of inflammation such as ESR or CRP). Subjective outcomes are based on the experience or opinion by the patient e.g. questions about perceived pain or general well-being.

Outcome measures - outcome measures are measurements of for example the effects of a treatment. They might include physical measurements – for example measuring blood pressure, or psychological measurements – such as measuring a sense of well-being.

P

Participant - a participant is someone who takes part in a research project. Sometimes research participants are referred to as research 'subjects'.

Patient information leaflet / patient information sheet - researchers must provide a patient information leaflet to everyone they invite to take part in a research study, to ensure people can make an informed decision about this. The leaflet explains what taking part will involve and should include details about:

- Why the research is being done, how long it will last, and what methods will be used the possible risks and benefits
- What taking part will practically involve, for example extra visits to a hospital or a researcher coming to interview someone at home
- What <u>interventions</u> are being tested, or what topics an interview will cover
- How the researchers will keep participants' information confidential
- What compensation is available to people if they are harmed as a result of taking part in the research
- Who to contact for further information
- How the results will be shared with others

Patient and Public Involvement (PPI) - 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.

STUDY DESIGN AND RESEARCH RELATED JARGON

Peer interviewing - peer interviewing is where people are interviewed by others who have a similar experience to them – their peers. For example, in a project to find out about children's experiences of after school care, children with experience of using after school care may act as peer interviewers, asking other children about their experience. Some researchers believe that this kind of interviewing enables people to talk more freely about their experience.

Peer review / refereeing - peer reviewing is where a <u>research proposal</u> or a report of research 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, or other professionals. Peer review helps to check the quality of a manuscript, report or research proposal.

Members of the public who act as peer reviewers may choose to comment on:

- Whether the research addresses an important and relevant question
- The methods used by researchers
- The quality of public involvement in research

Perspectives / user perspectives - a user perspective is often what people with experience of using health or social services are asked to bring when they get involved in research. They are asked to provide ideas, comments and suggestions based on the unique insight they have from their knowledge and experience of life with a health condition. They cannot be representative of everyone who uses a particular service, but they can offer their own perspective, and often that of other people.

Placebo - a placebo is a fake or dummy treatment that is designed to be harmless and to have no effect. It allows researchers to test for the 'placebo effect'. Placebos are used to help separate the real effect of the active ingredient from any benefit (or side effect) that the subject may experience by chance or purely by the acting of taking tablets. 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. The best placebos are identical to the real drug and help to maintain blinding in either single or double blind trials.

Prevalence - prevalence differs from <u>incidence</u> in that it does not convey information about risk. Prevalence is defined as the number of individuals with a certain disease in a population at a specified time divided by the number of individuals in the population at that time.

Prospective study - in prospective cohort studies participants are selected at the start of the study and data is collected on the participants exposure status and disease status over time. In a prospective cohort study the researchers can collect information directly from the participants using interviews, questionnaires and medical examinations or from other sources (e.g. medical records, X-ray data, blood samples).

Protocol / research protocol - a protocol is the plan for a piece of research. It usually includes information about:

- What question the research is asking and its importance/relevance
- The background and context of the research, including what other research has been done before
- How many people will be involved
- Who can take part
- The research method
- What will happen to the results and how they will be publicised

STUDY DESIGN AND RESEARCH RELATED JARGON

A protocol describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research ethics committee for approval.

Public health research - public health is concerned with promoting good health, preventing disease and protecting people from hazards, rather than treating illnesses. It covers topics like the control of infectious diseases, vaccinations, and helping people to adopt healthy lifestyles.

Public health research involves finding out new knowledge (or testing out existing ideas) to do with public health – so it might address questions about:

- The best ways to help people stop smoking
- How Bird Flu spreads.

Q

Quality of life - as well as measuring the physical effects of a treatment (for example changes to blood pressure), many studies now try to assess the impact of treatments on people's quality of life. For example, a 'quality of life' study might ask about: your mood and general sense of well-being; whether you feel more tired than usual; whether you are managing to do more things than before and whether your sleep patterns have changed

Qualitative research - 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 want to stop smoking. It won't ask how many people have tried to stop smoking. 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).

Quantitative research - deals with facts, figures and measurements, and produces data which can be readily analysed. Measurable data is gathered from a wide range of sources, and it is the analysis and interpretation of the relationships across this data that gives the information researchers are looking for. These data are collected using numbers, perhaps through questionnaires. The numbers are then examined using statistical tests to see if the results have happened by chance. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year, or what proportion of children have had an MMR vaccine, or whether a new drug lowers blood pressure more than the drugs that are usually used.

Questionnaire - a questionnaire is a prepared set of written questions used to obtain information from research participants. Questionnaires can be completed on paper, using a computer or with an interviewer.

R

Randomisation - if you take part in a randomised controlled trial, you will have an equal chance of receiving any of the treatments being compared. The decision about which treatment you'll receive is based on chance. A computer will decide which treatment you'll receive, not you or the doctor. This is called randomisation. Randomisation ensures that the groups of people receiving different

treatments in a trial are as similar as possible, except for the treatment they receive. This is important because it means that researchers can be sure that any differences between the groups are only due to the treatment. Randomisation is the best way of ensuring that the results of trials are not biased. For example, if a doctor chose which treatment a participant should receive as part of a trial, she or he might give the new treatment to sicker participants, or to younger participants. This would make the results of a trial unreliable. Randomisation helps prevent this kind of bias. **Randomised controlled trial -** a controlled trial compares two groups of people: an experimental group who receive the new treatment and a control group, who receive the usual treatment or a placebo. The control group allows the researchers to see whether the treatment they are testing is any more or less effective than the usual or standard treatment. In a randomised controlled trial, the decision about which group a person joins is random (that is based on chance).

Regression (e.g. linear, logistic) – Regression analysis are a statistical method to look at an association between certain factors (e.g. age, gender, disease activity) and an outcome of interest (e.g. the development of cardiovascular disease).

Representative - as a representative, you are expected to speak on behalf of a larger group of people. If you've been asked to get involved in research as a representative of a particular group, you may want to think about how you can be confident that you are representing a wider range of people's views, rather than just offering your own perspective.

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

Researcher - researchers are the people who do the research. They may do research for a living, and be based in a university, hospital or other institution, and/or they may be a service user or carer. **Research governance -** research governance is a process aimed at ensuring that 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 grant - research grants are given to enable researchers to carry out a particular piece of research. Usually, in order to get research grants, researchers have to write a research proposal and receive a positive peer review.

Research methods - research methods are the ways researchers collect or techniques and analyse information. So research methods include interviews, questionnaires, diaries, clinical trials, experiments, analysing documents or statistics, and watching people's behaviour. **Research partner -** the term research partner is used to describe people who get actively involved in research, to the extent that they are seen by their 'professional' colleagues as a partner, rather than someone who might be consulted occasionally. Partnership suggests that researchers and service users/carers have a relationship that involves mutual respect and equality.

Research proposal - this is usually an application form or set of papers that researchers have to complete to say what research they want to do and how they want to do it. It will also cover the aim of the research, what the research questions are, who will be involved (both as participants and in carrying out the research), the time-scale and the cost.

Research user group – Group of patients advising researchers about patient information sheets, protocols and lay summaries for grant applications.**Responsiveness -** the ability of an instrument (methods, questionnaires etc) to measure a significant change in disease activity over time.

Retrospective study - A retrospective cohort study means a study that takes a look back at events that already have taken place. For example, a look back at a patient's medical history or lifestyle. In these studies pre-existing data on exposures and outcomes from medical records or by means of questionnaires are used.

S

Sensitivity - The sensitivity of a screening test reflects the ability of the test to detect the disease when it is present. A test that is highly sensitive will detect a large proportion of people who indeed have the disease.

Service user or user - a service user is someone who uses or has used health and/or social care services because of illness or disability.

Side effects (adverse events) - side effects are undesired effects that are related to a treatment. For example, if you are given a drug to treat an illness and it makes you sick (e.g. dizziness, stomach ache or a rash), this would be described as a side effect. Clinical trials will often look at short- and long-term side effects related to a treatment. **Significant -** in research, statistical tests will show whether a result arose by chance, or whether it is unlikely to have happened by chance and can therefore be said to be significant (e.g. a statistically significant change in pain on a new drug).

Smallest detectable difference (SDD) - the SDD is the smallest statistically significant change in measurement results.

Social care research - Social care refers to a range of services provided across different settings, usually in the community. These include:

- Home care, day care and residential care for older people
- Residential care and fostering for children
- Support for parents of disabled children
- Supporting mental health service users, physically disabled people and people with learning difficulties
- Support for carers

Social care research involves finding out new knowledge (or testing out existing ideas) to do with social care – so social care research might address questions about:

- People's experience of using different home care services
- The best ways to train new foster parents.

Social responsibility – social responsibility describes the way a large corporation (for example the University of Manchester) aims to make a difference to the social and economic well-being of the local community and wider society through its activities including patient and public involvement and green impact.

Specificity - the specificity of a e.g. screening test is the ability of the test to identify non-disease in healthy individuals. A test that is highly specific will rarely produce false positive results.

Statistics and statistical analysis - statistics are a set of numbers (quantitative data) obtained through research. For example, the average age of a group of people, or the number of people using a service. Statistical analysis uses a set of mathematical rules to analyse quantitative data. It can help researchers decide what data means. For example, statistical analysis can assess whether any

difference seen between two groups of people (e.g. between the groups of people in a clinical trial) is likely to be a reliable finding or simply due to chance.

Systematic review - systematic reviews aim to bring together the results of all studies addressing a particular research question that has been carried out around the world. They provide a comprehensive and unbiased summary of the research. For example, one clinical trial may not give a clear answer about the effectiveness of a treatment. This might be because the difference between the treatments being tested was very small, or because only a small number of people took part in the trial. So systematic reviews are used to bring the results of a number of similar trials together, to piece together and assess the quality of all of the evidence. Combining the results from a number of trials may give a clearer picture.

T

Translational research – apply findings of research done in the laboratory in clinical studies or in clinical settings such as the hospital. It can also mean that observations made in clinic may lead to research questions which will be investigated in the laboratory.

U

User controlled research / user led research - user controlled research is research that is actively controlled, directed and managed by service users and their service user organisations.

User researcher - a user researcher is someone who uses or has used health and/or social care services because of illness or disability, who is also a researcher. Not all researchers who use health or social care services call themselves user researchers. Calling yourself a user researcher is making a statement about your identity as a service user as well as a researcher.

V

Validity (external) - the extent to which research findings apply to broader populations. A research study has external validity if its results can be generalized to the larger population.

Validity (internal) - the ability of an instrument (method, questionnaire) to measure what it has to measure (or what we expect to measure). Several characteristics of a study affect its internal validity. Are the two groups of people being compared similar in all the important characteristics that may affect the measurement data.

Variable (i.e. factor, outcome) - a variable is a factor you measure, such as pain, depression, disability, or CRP. Different variables are measured in different ways for example:

- Dichotomous or yes/no answers.
- Continuous measures (eg lengths, weight, visual analogue scale (VAS) pain).
- Discrete measures have to be whole numbers
- Categories such as non-smoker, ex-smoker or current smoker.

Variables can also be labelled as - :

- Primary – the main question the study is asking
- Secondary – the next question you would like to ask
- Clinical – health status, eg pain, disability
- Demographic – details such as age, gender

Visual Analogue Scale (VAS) **-** a linear scale ranging from e.g. 0 – 10 cm on which a patient scores how much pain / fatigue they are experiencing from 0 = no pain / fatigue to 10 = extreme pain / fatigue.

RHEUMATOLOGY AND DISEASE RELATED JARGON

A

Active disease - a condition which is developing and not currently under control.

Anaemia - a shortage of haemoglobin (oxygen-carrying pigment) in the blood which makes it more difficult for the blood to carry oxygen around the body. Anaemia can be caused by some rheumatic diseases such as rheumatoid arthritis or lupus, or by a shortage of iron in the diet. It can also be a side-effect of some drugs used to treat arthritis.

Analgesia - the term used to describe the range of drugs used to control pain from mild to strong treatments.

Ankylosing spondylitis (AS) - this is a chronic condition caused by inflammation of the joints and ligaments of the back, which affects the spine and may lead to stiffness in the back.

Antibody - a blood protein that forms in response to germs, viruses or any other substances that the body sees as foreign or dangerous. The role of antibodies is to attack these foreign substances and make them harmless.

Anti-CCP / ACPA (anti cyclic citrullinated peptide) **–** an auto-antibody measured in blood used to help in the diagnosis of rheumatoid arthritis and differentiate it from other types of arthritis; sometimes to help evaluate the prognosis of a person with rheumatoid arthritis.

Antiresorptive Drugs - a class of drugs used to prevent thinning of the bones.

Anti-TNF (anti-tumour necrosis factor) **-** TNF is a chemical made by the immune system. When made in the joints it causes the process of inflammation and joint damage. Treatment with anti-TNFs removes the TNF from the joints.

Arthritis - arthritis is a chronic condition marked by inflammation, pain and stiffness in the joints. More than 100 diseases fall under the arthritis category, each with its own subset of symptoms, causes and complications.

Arthritis Impact Measurement Scale (AIMS) **-** multidimensional patient-completed questionnaire on health status, useful for evaluating the outcome of arthritis treatments and programmes.

Autoimmune diseases - a host of diseases caused by the immune system mistakenly attacking the body's own cells, tissues and organs. Auto-immune diseases are marked by inflammation, but symptoms and complications vary greatly. Some of the most common auto-immune diseases are rheumatoid arthritis, lupus, scleroderma, multiple sclerosis and diabetes mellitus.

B

Biologics - a newer type of treatment for autoimmune diseases. These drugs target specific chemical messengers or cells that activate inflammation in the body.

Biomarkers - these are biologic molecules that are useful in measuring the presence or progression of a disease or the effects of a particular treatment.

BMI (Body Mass Index) **-** calculation (kg/height in meters*height in meters) used as a simple way of assessing whether a person is overweight or underweight.

Bone Density - bone density is measured by the amount of mineral in bones. Loss of mineral matter in the bone is one of several factors that can make the bones more brittle, which can lead to osteoporosis. Bone density is measured by a test called dual energy X-ray absorptiometry (DXA).

C

Capsule - the tough, fibrous sleeve of ligaments around a joint, which prevents the bones in the joint from moving too far. The inner layer of the capsule (the synovium) produces a fluid that helps to nourish the cartilage and lubricate the joint.

Carpal tunnel - the passageway within the wrist through which the tendons which bend the fingers and the median nerve pass.

Cartilage - cartilage is a hard but slippery coating on the end of each bone. In certain diseases, such as osteoarthritis, cartilage breaks down and wears away.

Cognitive Behavioural Therapy (CBT) **-** is a talking therapy used to help people understand that their negative beliefs or 'negative self-talk' are often inaccurate and can lead to self-defeating emotions and behaviours. The aim of the therapy is to challenge these inaccurate, negative thoughts to help people feel better emotionally.

Collagen - collagen is a fibrous protein that functions as a building block of the skin, the tendons, the bones, as well as other connective tissues.

Co-morbidity (multi-morbidity) - the existence of two chronic diseases in one person at the same time; for example, a patient with the joint disease rheumatoid arthritis and the skin disease psoriasis or a patients with rheumatoid arthritis having a cardiovascular disease as well. Multi-morbidity is people with more than one co-morbidity.

Computerised Tomography (CT) scan **-** a type of scan that records images of sections or slices of the body using X-rays. These images are transformed by a computer into cross sectional pictures.

Connective tissue - joints, bones, cartilage and other tissue that supports and holds together different parts of the body.

Corticosteroids (glucocorticoids) - a medication used for relief of inflammation and pain, sometimes called steroids. This is a family of drugs used to treat numerous autoimmune and inflammatory conditions.

C-reactive protein (CRP) **-** a protein found in the blood. The level of C-reactive protein in the blood rises in response to inflammation and a blood test for the protein can therefore be used as a measure of inflammation or disease activity.

CREST - one of two types of scleroderma, an autoimmune disorder characterized by thickening of the skin. Unlike the more severe form of scleroderma called progressive systemic sclerosis, which affects internal organs, CREST is limited to the skin of the hands and face. CREST stands for Calcinosis, Raynaud's phenomenon, Esophageal involvement, Sclerodactyly and Telangiectasia. (See Progressive systemic sclerosis)

Cytokines - cytokines are immune system cells (found in synovial fluid) that have been linked to the rheumatoid arthritis disease process of inflammation and cartilage destruction.

D

Dietician - a specialist in the study of nutrition and diet.

Disability - a limitation in the performance of roles and tasks that society expects an individual to perform. The expression of a gap between a person's capabilities and the demands of an environment.

Disease Activity Score (DAS) - a score used to assess the level of disease activity in people with rheumatoid arthritis and guide treatment decisions. It is calculated through an examination of the joints (number of swollen and tender joints), a consultation with the health care professional regarding the current level of disease activity and a blood test. The DAS28 is based on 28 joints and DAS44 based on 44 joints including ankles and feet.

Disease-modifying anti-rheumatic drugs (DMARD) - drugs used in rheumatoid arthritis and some other rheumatic diseases to suppress the disease and reduce inflammation. Unlike painkillers and non-steroidal anti-inflammatory drugs (NSAIDs), DMARDs treat the disease itself rather than just reducing the pain and stiffness caused by the disease. Examples of DMARDs are methotrexate, sulfasalazine, gold, infliximab, etanercept and adalimumab.

E

Enthesitis - inflammation of the sites (entheses) where tendons or ligaments attach to bone.

Erythrocyte Sedimentation Rate (ESR) - a test that shows the level of inflammation in the body and can help in the diagnosis of rheumatoid arthritis.

F

Facet joints - the facet joints are small joints at the back of the spine between the vertebrae that allow the spinal column to move.

Fibromyalgia (or Fibromyalgia Syndrome (FMS))- fibromyalgia is a chronic disorder that causes widespread musculoskeletal pain, fatigue, and multiple tender points in localized areas, such as the neck, spine, shoulders, and hips. The syndrome is marked by symptoms including sleep disturbances, morning stiffness, irritable bowel syndrome, anxiety, and other symptoms.

Fibrosis - the formation of scar tissue sometimes caused by an exaggerated healing process. When it occurs in one of the body's vital organs, fibrosis may impair the function of that organ.

Flare up (or Flare) - a period in which the symptoms of a disease reappear or worsen.

Full Blood Count (FBC) – laboratory tests to determine the general health status and to screen for a variety of disorders, such as anaemia and infection, inflammation, nutritional status and exposure to toxic substances.

G

General practitioner (GP) **-** the first point of contact for all patients with any type of illness. They are responsible for referring patients to specialists.

Glucose Test - blood test to determine whether or not your blood glucose level is within normal ranges; to screen for, diagnose and monitor diabetes, and hypoglycaemia (low blood glucose).

H

Haemoglobin (Hb) - this is a protein in the red blood cells which is responsible for carrying oxygen in the cells to the body.

Health Assessment Questionnaire (HAQ) - a questionnaire that asks whether people are to carry out normal daily tasks around the home such as bathing, getting in and out of a chair and shopping, measuring functional mobility.

Hep B (Hepatitis B) - hepatitis B antibodies are produced in response to exposure to the hepatitis B virus (HBV). The tests detect the presence of this antibody or of parts (antigens) of the virus itself. It is used to diagnose and follow the course of an infection with hepatitis B or to determine if the vaccine against hepatitis B has produced the desired level of immunity.

Hep C (Hepatitis C) - blood test to determine if you've been exposed to the hepatitis C virus and have the antibodies in your blood.

HLA-B27 (Human Leucocyte Antigen-B27) - people who have this gene are more likely to have conditions such as reactive arthritis, psoriatic arthritis or ankylosing spondylitis.

Homeopathy - a complementary medicine that uses a dilute active substance which would normally cause symptoms similar to those being treated e.g. using a crushed bee sting to treat a bee sting.

Hydrotherapy - exercises that take place in water (usually a warm, shallow swimming pool or a special hydrotherapy bath) which can improve mobility, help relieve discomfort and promote recovery from injury.

I

Immune system - the tissues that enables the body to resist infection. They include the thymus (a gland that lies behind the breastbone), the bone marrow and the lymph nodes.

Immunoglobulins (also known as antibodies) - are proteins in the blood or other body fluids used by the body to neutralise bacteria and viruses.

Immunology - immunology is the study of the immune system and its reaction to pathogens, as well as its malfunctions, such as allergies and autoimmune diseases.

Immunosuppressant drugs - drugs that suppress the actions of the immune system. They're often used in conditions such as rheumatoid arthritis where the immune system attacks the body's own tissues.

Inflammation - a normal reaction to injury or infection of living tissues. The flow of blood increases, resulting in heat and redness in the affected tissues, and fluid and cells leak into the tissue, causing swelling.

Interleukin-1 (IL-1) - is one of the pro-inflammatory cytokines in the immune system thought to play a role in the disease process of rheumatoid arthritis, including bone erosion.

J

Joint capsule - a tough membrane sac that holds all the bones and other joint parts together.

Joint damage – damage of the bones and/or cartilage of the joints affecting the movement of joints. Joint damage can be detected by ultrasound or by other imaging techniques such as X-rays.

Juvenile idiopathic arthritis (JIA) - juvenile idiopathic arthritis is arthritis that causes joint inflammation and stiffness for more than six weeks in children under 16 years. JIA can affect any joint and mobility may become limited. There are seven types of JIA, one of them can affect the internal organs.

L

Larsen score – a score to measure deformities (erosions and narrowing of bone and cartilage) on X-rays of hands and feet in patients with rheumatoid arthritis.

Ligaments - tough, fibrous bands anchoring the bones on either side of a joint and holding the joint together. In the spine they're attached to the vertebrae and restrict spinal movements, therefore giving stability to the back.

Liver Function Tests (LFTs) - are used to detect any impact on the liver as a result of the prescribed treatment for inflammatory arthritis.

Lupus (Systemic Lupus Erythematosis SLE) - lupus is a complex and poorly understood condition that affects many parts of the body and causes symptoms ranging from mild to life-threatening. Some common symptoms of lupus include: fatigue, skin rash, joint pain and swelling. Lupus is an

autoimmune condition, which means it is caused by problems with the immune system (the body's natural defence against illness and infection). In people with lupus, for reasons not clearly understood, the immune system starts to attack healthy cells, tissue and organs. As with other more common autoimmune conditions, such as rheumatoid arthritis, it is thought a combination of genetic and environmental factors is responsible for triggering lupus in certain people.

M

Metabolic Syndrome (MetS) – metabolic syndrome is the medical term for a combination of diabetes, high blood pressure and obesity. It puts you at greater risk of heart disease, stroke and other conditions affecting blood vessels.

MCV (Mean Cell Volume) - a blood test to determine the size of the red blood cells and guide the diagnosis of anaemia (low numbers of red blood cells or low levels of haemoglobin within the cell).

MRI (Magnetic Resonance Imaging) - a diagnostic test for viewing the body's internal structures, especially soft tissues.

Multi Disciplinary Team (MDT) - a group of health care and social care professionals who provide different services for patients in a co-ordinated way.

Musculoskeletal system - the system of muscles, tendons, ligaments, bones, joints and associated tissues that move the body and maintain its form.

N

Nerve block - an injection of local anaesthetic (often combined with a steroid preparation) around a nerve which causes temporary loss of sensation.

Non-steroidal anti-inflammatory drugs (NSAIDs) - drugs prescribed for different kinds of arthritis that reduce inflammation and control pain, swelling and stiffness. Common examples include ibuprofen, naproxen and diclofenac.

O

Occupational therapist (OT) - a therapist who helps people to get on with daily activities (e.g. dressing, eating, bathing) by giving practical advice on aids, appliances and altering techniques.

Osteoarthritis (OA) - is a joint disease that affects mainly cartilage of the joints. It is the most common type of arthritis, especially among older people. It is also called degenerative joint disease.

Osteoporosis - a condition where bones become less dense and more fragile, which means they break or fracture more easily.

RHEUMATOLOGY AND DISEASE RELATED JARGON

P

Personal Care - Personal Care refers to assistance with activities of daily living. It is usually provided by home health aides (some aides are non-licensed), transportation and shopping aides, certified nursing assistants or therapy aides. It may be provided by home health agencies, adult foster care or adult day care, as well as in residential and assisted living facilities.

Phlebotomist - a professional who draws blood for analysis or transfusion.

Physiotherapist - a therapist who helps to keep people's joints and muscles moving, helps ease pain and keeps people mobile.

Plasma viscosity (PV) - a screening test that measures the thickness or stickiness of the fluid in which blood cells are suspended. It is used as an indicator of disease activity in a number of conditions including rheumatoid arthritis, psoriatic arthritis and lupus.

Platelets (also called thrombocytes) - platelets are tiny blood particles that help the clotting process by sticking to the lining of blood vessels. Platelets are made in the bone marrow and survive in the circulatory system for an average of about 10 days before being removed from the body by the spleen.

Podiatrist - a trained foot specialist.

Progressive systemic sclerosis - one of two types of scleroderma, an autoimmune disease characterized by thickening of the skin and by hardening of the tissue of some internal organs. The other form of scleroderma is called CREST.

Proton-pump inhibitor (PPI) - a drug that acts on an enzyme in the cells of the stomach to reduce the secretion of gastric acid. They are often prescribed along with non-steroidal anti-inflammatory drugs (NSAIDs) to reduce side-effects from the NSAIDs.

Psoriatic arthritis (PsA) - a condition that causes inflammation in and around the joints usually affecting those who already have psoriasis (a scaly skin rash) but can precede any possible skin problems which may or may not develop.

R

Radiographer - a member of the health care team who takes X-rays and scans.

Raynaud's syndrome (Raynaud's phenomenon) - this is a condition characterized by blood vessel spasms in the fingers, toes, ears or nose, usually brought on by exposure to cold. Raynaud's phenomenon can occur in people with autoimmune disorders such as rheumatoid arthritis, lupus and scleroderma.

Reactive arthritis - a relatively short-lived condition causing painful swelling of the joints. It develops after an infection of the bowel or genital tract, or less frequently after a throat infection.

Remission - the disappearance of the signs and symptoms of a disease.

Rheumatoid arthritis (RA) - an autoimmune disease that causes inflammation in the joints and less commonly inflammation in other parts of the body which may result in damage of the joints.

Rheumatoid factor (RF) - a blood protein produced by a reaction in the immune system. About 65-70% of people with rheumatoid arthritis test positive for this protein. However, it is possible to have rheumatoid arthritis or another form of inflammatory arthritis with a negative RF.

Rheumatoid nodule - a small lump of tissue which forms under the skin. Nodules are most common on the elbows, where they are usually painless. Nodules on the fingers can be a nuisance.

Rheumatology - a field of internal medicine devoted to the diagnosis and treatment of rheumatic diseases, which involve joints, muscles, skin, internal organs and tendons. Rheumatic symptoms may have underlying causes not related to rheumatology.

Rheumatologist - a consultant physician specialising in rheumatological diseases.

S

Sciatica - pain felt in the leg due to irritation of the sciatic nerve, a major nerve running from the spine to the leg. The pain is usually felt in the buttock, thigh and calf but can go all the way down to the toes.

Scleroderma - scleroderma is an autoimmune disorder marked by hardening of the body's connective tissue, but can also involve internal organs such as the heart, lungs, kidneys and the gastrointestinal tract. There are two types of scleroderma: CREST, which is limited to the skin, and progressive systemic sclerosis, which affects internal organs.

Secondary care - the second stage of the health care system, where a patient is referred by their GP for specialist treatment and care.

Self-management - is defined as a constant process of behavioural choices and decision making which can be achieved by changing knowledge, skills and attitudes and initiating behaviour change in patients.

Septic arthritis - also known as infective arthritis and is very different from reactive arthritis. It occurs when there is an active infection within one joint but can also affect additional joints. It is a medical emergency and requires immediate hospital treatment.

Sharp Score - an X-ray measurement of changes in joint damage.

Sjögren's syndrome (SS) - is a condition that mainly affects the glands that produce saliva and tears causing a reduction in the normal levels. It may be diagnosed as a primary condition or a secondary condition to rheumatoid arthritis.

Social worker - a professional responsible for helping individuals, groups or communities to enhance or restore their capacity for social functioning.

Specialist nurse (Clinical Nurse Specialist) **-** a senior nurse who has additional training in their specialism (e.g. rheumatology) enabling him/her to assess and monitor responses to treatment, to advise on the drugs prescribed, to teach injection techniques and offer support often via a designated Helpline.

Specialist registrar (SpR) - a doctor in the United Kingdom and Republic of Ireland who is receiving advanced training in a specialist field of medicine in order to become a consultant.

Synovial fluid - the fluid produced within the joint capsule that helps to nourish the cartilage and lubricate the joint.

Synovium - the inner membrane of the joint capsule that produces synovial fluid.

Systemic disease - a disease that can affect the whole body, or many parts of the body, including the internal organs.

T

T-cells - T-cells are a type of white blood cell which defend the body against disease but sometimes they start attacking the body's own tissue as in rheumatoid arthritis.

Tendon - a strong, fibrous band or cord that anchors muscle to bone.

Thyroid Function Tests (TFTs) - are a group of tests that are requested together to help evaluate the function of the thyroid gland and to help to diagnose thyroid disorders.

Triglycerides - a blood test to assess the level of triglycerides (the main component of animal fats & vegetable oils). High levels are linked to hardening of the arteries and the risk of heart disease and stroke.

Tumor necrosis factor (TNF) - a protein produced by white blood cells as means of controlling disease and breaking down developing cancer cells, or neoplasms. As a side effect, this defense mechanism can cause inflammation in the body and may trigger conditions such as rheumatoid arthritis.

U

Ultrasound scan - a type of scan that uses high-frequency sound waves to examine and build up pictures of the inside of the body.

V

Vasculitis - inflammation in the walls of blood vessels. This can cause the blood flow to be reduced. Vasculitis can occur on its own (primary vasculitis) or as part of an established disease (secondary vasculitis) when it may be associated with rheumatoid arthritis, Sjogren's syndrome or lupus.

W

Wegener's Granulomatosis - Wegener's granulomatosis is characterized by inflammation of the blood vessels, which in turn interferes with normal blood flow. The condition can cause damage to internal organs in the body, but affects mainly the respiratory tract: the sinuses, nose, trachea and lungs. Wegener's can also affect the kidneys. Wegener's can strike men and women of any age. It is more prevalent in Caucasians than in African Americans.

X

X-Ray – an imaging test used to detect disease or injury to the bones and joints.

GENETIC AND BASIC RESEARCH RELATED JARGON

A

ACGT - ACGT is an acronym for the four types of bases found in a DNA molecule: adenine (A), cytosine (C), guanine (G), and thymine (T). A DNA molecule consists of two strands wound around each other, with each strand held together by bonds between the bases. Adenine pairs with thymine, and cytosine pairs with guanine. The sequence of bases in a portion of a DNA molecule, called a gene, carries the instructions needed to assemble a protein.

Allele - an allele is one of two or more versions of a gene. An individual inherits two alleles for each gene, one from each parent. If the two alleles are the same, the individual is homozygous for that gene. If the alleles are different, the individual is heterozygous. A single allele for each locus is inherited separately from each parent (e.g., at a locus for eye colour the allele might result in blue or brown eyes).

Amino acid - amino acids are a set of 20 different molecules used to build proteins. Proteins consist of one or more chains of amino acids called polypeptides. The sequence of the amino acid chain causes the polypeptide to fold into a shape that is biologically active. The amino acid sequences of proteins are encoded in the genes.

Antibody - an antibody is a protein component of the immune system that circulates in the blood, recognizes foreign substances like bacteria and viruses, and neutralizes them. After exposure to a foreign substance, called an antigen, antibodies continue to circulate in the blood, providing protection against future exposures to that antigen.

Apoptosis - apoptosis is the process of programmed cell death. It is used during early development to eliminate unwanted cells; for example, those between the fingers of a developing hand. In adults, apoptosis is used to rid the body of cells that have been damaged beyond repair

Autosome - an autosome is any of the numbered chromosomes, as opposed to the sex chromosomes. Humans have 22 pairs of autosomes and one pair of sex chromosomes (the X and Y). Autosomes are numbered roughly in relation to their sizes. That is, chromosome 1 has approximately 2,800 genes, while chromosome 22 has approximately 750 genes.

B

Bacteria - bacteria are small single-celled organisms. Bacteria are found almost everywhere on Earth and are vital to the planet's ecosystems. Some species can live under extreme conditions of temperature and pressure. The human body is full of bacteria, and in fact is estimated to contain more bacterial cells than human cells. Most bacteria in the body are harmless, and some are even helpful. A relatively small number of species cause disease.

Base pair (bp) - a base pair is two chemical bases bonded to one another forming a "rung of the DNA ladder." The DNA molecule consists of two strands that wind around each other like a twisted ladder. Each strand has a backbone made of alternating sugar (deoxyribose) and phosphate groups. Attached to each sugar is one of four bases--adenine (A), cytosine (C), guanine (G), or thymine (T). The two strands are held together by hydrogen bonds between the bases, with adenine forming a base pair with thymine, and cytosine forming a base pair with guanine.

Base sequence - the order of nucleotide bases in a DNA molecule.

GENETIC AND BASIC RESEARCH RELATED JARGON

Bioinformatics - bioinformatics is a sub-discipline of biology and computer science concerned with the acquisition, storage, analysis, and dissemination of biological data, most often DNA and amino acid sequences. Bioinformatics uses computer programs for a variety of applications, including determining gene and protein functions, establishing evolutionary relationships, and predicting the three-dimensional shapes of proteins.

C

cDNA - See complementary DNA.

Candidate gene - a candidate gene is a gene whose chromosomal location is associated with a particular disease or other phenotype. Because of its location, the gene is suspected of causing the disease or other phenotype. A candidate gene is a gene whose chromosomal location fits with a particular disease or phenotype that you're looking for.

Cell - the basic structural unit of all living organisms. A human cell is made up a central nucleus (containing DNA) a cytoplasm and an outer cell membrane.

Centimorgan (cM) - a unit of measure of recombination frequency. One centimorgan is equal to a 1% chance that a marker at one genetic locus will be separated from a marker at a second locus due to crossing over in a single generation. In human beings, 1 centimorgan is equivalent, on average, to 1 million base pairs.

Centromere - a centromere is a constricted region of a chromosome that separates it into a short arm (p) and a long arm (q). During cell division, the chromosomes first replicate so that each daughter cell receives a complete set of chromosomes. Following DNA replication, the chromosome consists of two identical structures called sister chromatids, which are joined at the centromere.

Chromatid - the two identical halves of a chromosome produced for cell division and meiosis.

Chromosome - a chromosome is an organized package of DNA found in the nucleus of the cell. Different organisms have different numbers of chromosomes. Humans have 23 pairs of chromosomes--22 pairs of numbered chromosomes, called autosomes, and one pair of sex chromosomes, X and Y. Each parent contributes one chromosome to each pair so that offspring get half of their chromosomes from their mother and half from their father.

Clones - a group of cells derived from a single ancestor.

cM - see centimorgan.

Codon - a codon is a trinucleotide sequence of DNA or RNA that corresponds to a specific amino acid. The genetic code describes the relationship between the sequence of DNA bases (A, C, G, and T) in a gene and the corresponding protein sequence that it encodes. The cell reads the sequence of the gene in groups of three bases. There are 64 different codons: 61 specify amino acids while the remaining three are used as stop signals.

Complementary sequences - nucleic acid base sequences that can form a double-stranded structure by matching base pairs; the complementary sequence to G-T-A-C is C-A-T-G.

Complex disease - a complex disease is caused by the interaction of multiple genes and environmental factors. Complex diseases are also called multifactorial. Examples of complex diseases include cancer and heart disease.

Congenital - congenital conditions are those present from birth. Birth defects are described as being congenital. They can be caused by a genetic mutation, an unfavorable environment in the uterus, or a combination of both factors.

Conserved sequence - a base sequence in a DNA molecule (or an amino acid sequence in a protein) that has remained essentially unchanged throughout evolution.

Crossing over - crossing over is the swapping of genetic material that occurs in the germ line. During the formation of egg and sperm cells, also known as meiosis, paired chromosomes from each parent align so that similar DNA sequences from the paired chromosomes cross over one another. Crossing over results in a shuffling of genetic material and is an important cause of the genetic variation seen among offspring.

Cytoplasm - cytoplasm is the gelatinous liquid that fills the inside of a cell. It is composed of water, salts, and various organic molecules. Some intracellular organelles, such the nucleus and mitochondria, are enclosed by membranes that separate them from the cytoplasm.

D

Diploid - a full set of genetic material, consisting of paired chromosomes one chromosome from each parental set. Most animal cells except the gametes have a diploid set of chromosomes. The diploid human genome has 46 chromosomes. Compare haploid.

Dizygotic - two cells having been fertilised at the same time (often resulting in twins.)

DNA (deoxyribonucleic acid) - DNA is the chemical name for the molecule that carries genetic instructions in all living things. The DNA molecule consists of two strands that wind around one another to form a shape known as a double helix. Each strand has a backbone made of alternating sugar (deoxyribose) and phosphate groups. Attached to each sugar is one of four bases--adenine (A), cytosine (C), guanine (G), and thymine (T). The two strands are held together by bonds between the bases; adenine bonds with thymine, and cytosine bonds with guanine. The sequence of the bases along the backbones serves as instructions for assembling protein and RNA molecules.

DNA replication - the use of existing DNA as a template for the synthesis of new DNA strands. In humans and other eukaryotes, replication occurs in the cell nucleus.

DNA sequencing - DNA sequencing is a laboratory technique used to determine the exact sequence of bases (A, C, G, and T) in a DNA molecule. The DNA base sequence carries the information a cell needs to assemble protein and RNA molecules. DNA sequence information is important to scientists investigating the functions of genes. The technology of DNA sequencing was made faster and less expensive as a part of the Human Genome Project.

Dominant - dominant refers to the relationship between two versions of a gene. Individuals receive two versions of each gene, known as alleles, from each parent. If the alleles of a gene are different, one allele will be expressed; it is the dominant gene. The effect of the other allele, called recessive, is masked. E.g. brown is the dominant eye colour.

GENETIC AND BASIC RESEARCH RELATED JARGON

Double helix - the shape that two linear strands of DNA assume when bonded together.

Duplication - duplication of a sequence of DNA or section of chromosome.

E

Electrophoresis - a method of separating large molecules (such as DNA fragments or proteins) from a mixture of similar molecules. An electric current is passed through a medium containing the mixture, and each kind of molecule travels through the medium at a different rate, depending on its electrical charge and size. Separation is based on these differences. Agarose and acrylamide gels are the media commonly used for electrophoresis of proteins and nucleic acids.

Enzyme - an enzyme is a biological catalyst and is almost always a protein. It speeds up the rate of a specific chemical reaction in the cell. The enzyme is not destroyed during the reaction and is used over and over. A cell contains thousands of different types of enzyme molecules, each specific to a particular chemical reaction.

Epigenetics - heritable changes caused by the activation and deactivation of genes without any change in the underlying DNA sequence of the organism. The word epigenetics is of Greek origin and literally means over and above (epi) the genome.

Eukaryote - cell or organism with membrane-bound, structurally discrete nucleus and other well-developed subcellular compartments. Eukaryotes include all organisms except viruses, bacteria, and blue-green algae. Compare prokaryote. See chromosomes.

Exogenous DNA - DNA originating outside an organism. E.g. viral.

Exons - the protein-coding DNA sequences of a gene. Compare introns.

F

First degree relative - a first degree relative is a family member who shares about 50 percent of their genes with a particular individual in a family. First degree relatives include parents, offspring, and siblings.

Flow cytometry - analysis of biological material by detection of the light-absorbing or fluorescing properties of cells or sub-cellular fractions (i.e., chromosomes) passing in a narrow stream through a laser beam. An absorbance or fluorescence profile of the sample is produced. Automated sorting devices, used to fractionate samples, sort successive droplets of the analysed stream into different fractions depending on the fluorescence emitted by each droplet.

GENETIC AND BASIC RESEARCH RELATED JARGON

G

Gene - the gene is the basic physical unit of inheritance. Genes are passed from parents to offspring and contain the information needed to specify traits. Genes are arranged, one after another, on structures called chromosomes. A chromosome contains a single, long DNA molecule, only a portion of which corresponds to a single gene. Humans have approximately 20,000 genes arranged on their chromosomes.

Gene expression - gene expression is the process by which the information encoded in a gene is used to direct the assembly of a protein molecule. The cell reads the sequence of the gene in groups of three bases. Each group of three bases (codon) corresponds to one of 20 different amino acids used to build the protein. Expressed genes include those that are transcribed into mRNA and then translated into protein and those that are transcribed into RNA but not translated into protein (e.g., transfer and ribosomal RNAs).

Gene families - groups of closely related genes that make similar products.

Gene product - the biochemical material, either RNA or protein, resulting from expression of a gene. The amount of gene product is used to measure how active a gene is; abnormal amounts can be correlated with disease-causing alleles.

Gene therapy - insertion of normal DNA directly into cells to correct a genetic defect.

Genetic code - the sequence of nucleotides, coded in triplets (codons) along the mRNA, that determines the sequence of amino acids in protein synthesis. The DNA sequence of a gene can be used to predict the mRNA sequence, and the genetic code can in turn be used to predict the amino acid sequence.

Genetic counselling - information and support provided by a specialist doctor, usually a geneticist, to parents who have known conditions in their families or who are concerned about the future possibility of genetically transmitted conditions.

Genetics - the study of the patterns of inheritance of specific traits.

Genome – the genome is the entire set of genetic instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes, found in the nucleus. These chromosomes, taken together, contain approximately 3.1 billion bases of DNA sequence and 20,000-25,000 genes.

Genome Wide Association studies (GWAS) - a genome-wide association study (GWAS) is an approach used in genetics research to associate specific genetic variations with particular diseases. The method involves scanning the genomes from many different people and looking for genetic markers that can be used to predict the presence of a disease. Once such genetic markers are identified, they can be used to understand how genes contribute to the disease and develop better prevention and treatment strategies.

Genotype - a genotype is an individual's collection of genes. The term also can refer to the two alleles inherited for a particular gene. The genotype is expressed when the information encoded in the genes' DNA is used to make protein and RNA molecules. The expression of the genotype contributes to the individual's observable traits, called the phenotype.

GENETIC AND BASIC RESEARCH RELATED JARGON

H

Haploid - a single set of chromosomes (half the full set of genetic material), present in the egg and sperm cells of animals and in the egg and pollen cells of plants. Human beings have 23 chromosomes in their reproductive cells. Compare diploid. Haploid is the quality of a cell or organism having a single set of chromosomes. Organisms that reproduce asexually are haploid. Sexually reproducing organisms are diploid (having two sets of chromosomes, one from each parent). In humans, only their egg and sperm cells are haploid.

Haplotype - a haplotype is a set of DNA variations, or polymorphisms, that tend to be inherited together (see also linkage disequilibrium) . A haplotype can refer to a combination of alleles or to a set of single nucleotide polymorphisms (SNPs) found on the same chromosome. Information about haplotypes is being collected by the International HapMap Project and is used to investigate the influence of genes on disease.

Heterozygosity - heterozygous refers to having inherited different forms of a particular gene from each parent. A heterozygous genotype stands in contrast to a homozygous genotype, where an individual inherits identical forms of a particular gene from each parent.

Homologous chromosomes - a pair of chromosomes containing the same linear gene sequences, each derived from one parent.

Homozygote - an individual with both identical alleles (versions of a single gene) at one locus (position). Homozygous is a genetic condition where an individual inherits the same alleles for a particular gene from both parents.

Hybridisation - hybridization is the process of combining two complementary single-stranded DNA or RNA molecules and allowing them to form a single double-stranded molecule through base pairing. In a reversal of this process, a double-stranded DNA (or RNA, or DNA/RNA) molecule can be heated to break the base pairing and separate the two strands. Hybridization is a part of many important laboratory techniques such as polymerase chain reaction and Southern blotting.

I

Imprinting - patterns of inheritance affected by whether the inheritance was from the mother or father.

In situ hybridisation - in situ hybridization is a laboratory technique in which a single-stranded DNA or RNA sequence called a probe is allowed to form complementary base pairs with DNA or RNA present in a tissue or chromosome sample. The probe has a chemical or radioactive label attached to it so that its binding can be observed.

Informatics - the study of the application of computer and statistical techniques to the management of information. In genome projects, informatics includes the development of methods to search databases quickly, to analyse DNA sequence information, and to predict protein sequence and structure from DNA sequence data.

Inheritance - the passing of familial elements from one generation to the next.

Introns - the DNA base sequences interrupting the protein-coding sequences of a gene; these sequences are transcribed into RNA but are cut out of the message before it is translated into protein. Compare exons.

In vitro - outside a living organism. E.g. in a laboratory test tube.

In vivo. – inside a living organism e.g. the human being.

K

Karyotype - a photomicrograph of an individual's chromosomes arranged in a standard format showing the number, size, and shape of each chromosome type; used in low-resolution physical mapping to correlate gross chromosomal abnormalities with the characteristics of specific diseases.

Kilobase (kb) - unit of length for DNA fragments equal to 1000 nucleotides.

Knock-out - a knockout typically refers to an organism that has been genetically engineered to lack one or more specific genes. Scientists create knockouts (often in mice) so that they can study the impact of the missing genes and learn something about the genes' function.

L

Linkage Disequilibrium (LD)- the close association of genes or other DNA sequences on the same chromosome, that descend from the same ancestral chromosone. The closer two genes are to each other on the chromosome, the greater the probability that they will be inherited together and not disrupted by recombination, see also crossing over.

Locus (pl. loci) - the position on a chromosome of a gene or other chromosome marker; also, the DNA at that position. So it's really the physical location of a gene or of a DNA polymorphism on a chromosome. The use of locus is sometimes restricted to mean regions of DNA that are expressed. See gene expression. The plural of locus is "loci".

Lymphocyte - a lymphocyte is a type of white blood cell that is part of the immune system. There are two main types of lymphocytes: B cells and T cells. The B cells produce antibodies that are used to attack invading bacteria, viruses, and toxins. The T cells destroy the body's own cells that have themselves been taken over by viruses or become cancerous.

M

Mapping - mapping is the process of making a representative diagram cataloging the genes and other features of a chromosome and showing their relative locations. Cytogenetic maps are made using photomicrographs of chromosomes stained to reveal structural variations. Genetic maps use the idea of linkage to estimate the relative locations of genes. Physical maps, made using

recombinant DNA (rDNA) technology, show the actual physical locations of landmarks along a chromosome.

Marker - a marker is a DNA sequence with a known physical location on a chromosome. Markers can help link an inherited disease with the responsible genes. DNA segments close to each other on a chromosome tend to be inherited together. Markers are used to track the inheritance of a nearby gene that has not yet been identified but whose approximate location is known. The marker itself may be a part of a gene or may have no known function.

Megabase (Mb) - unit of length for DNA fragments equal to 1 million nucleotides and roughly equal to 1 cM.

Messenger RNA (mRNA) - messenger RNA (mRNA) is a single-stranded RNA molecule that is complementary to one of the DNA strands of a gene. The mRNA is an RNA version of the gene that leaves the cell nucleus and moves to the cytoplasm where proteins are made. During protein synthesis, an organelle called a ribosome moves along the mRNA, reads its base sequence, and uses the genetic code to translate each three-base triplet, or codon, into its corresponding amino acid.

Microarray Technology - microarray technology is a developing technology used to study the expression of many genes at once. It involves placing thousands of gene sequences in known locations on a glass slide called a gene chip. A sample containing DNA or RNA is placed in contact with the gene chip. Complementary base pairing between the sample and the gene sequences on the chip produces light that is measured. Areas on the chip producing light identify genes that are expressed in the sample.

Microbiome - the human microbiome is the aggregate of microorganisms, a microbiome that resides on the surface and in deep layers of skin, in the saliva and oral mucosa, in the conjunctiva, and in the gastrointestinal tracts.

Mitochondria - mitochondria are membrane-bound cell organelles (mitochondrion, singular) that generate most of the chemical energy needed to power the cell's biochemical reactions. Chemical energy produced by the mitochondria is stored in a small molecule called adenosine triphosphate (ATP). Mitochondria contain their own small chromosomes. Generally, mitochondria, and therefore mitochondrial DNA, are inherited only from the mother.

Mitosis - cell division producing two genetically identical cells.

Multiplexing - a sequencing approach that uses several pooled samples simultaneously, greatly increasing sequencing speed.

Mutation - a mutation is a change in a DNA sequence. Mutations can result from DNA copying mistakes made during cell division, exposure to ionizing radiation, exposure to chemicals called mutagens, or infection by viruses. Germ line mutations occur in the eggs and sperm and can be passed on to offspring, while somatic mutations occur in body cells and are not passed on.

N

Nucleic acid - nucleic acid is an important class of macromolecules found in all cells and viruses. The functions of nucleic acids have to do with the storage and expression of genetic information. Deoxyribonucleic acid (DNA) encodes the information the cell needs to make proteins. A related

type of nucleic acid, called ribonucleic acid (RNA), comes in different molecular forms that participate in protein synthesis.

Nucleotide - a subunit of DNA or RNA consisting of a nitrogenous base (adenine, guanine, thymine, or cytosine in DNA; adenine, guanine, uracil, or cytosine in RNA), a phosphate molecule, and a sugar molecule (deoxyribose in DNA and ribose in RNA). Thousands of nucleotides are linked to form a DNA or RNA molecule.

Nucleus - a nucleus is a membrane-bound organelle that contains the cell's chromosomes. Pores in the nuclear membrane allow for the passage of molecules in and out of the nucleus.

P

PCR - see polymerase chain reaction.

Peptide -a peptide is one or more amino acids linked by chemical bonds. The term also refers to the type of chemical bond that joins the amino acids together. A series of linked amino acids is a polypeptide. The cell's proteins are made from one or more polypeptides.

Peripheral blood mononuclear cell (PBMC) - PBMCs are any blood cells having a round nucleus (opposed to a lobed nucleus). For example: a lymphocyte, a monocyte or a macrophage. These blood cells are a critical component in the immune system to fight infection and adapt to intruders.

Personalized medicine (stratified medicine) - personalized medicine is an emerging practice of medicine that uses an individual's genetic profile to guide decisions made in regard to the prevention, diagnosis, and treatment of disease. Knowledge of a patient's genetic profile can help doctors select the proper medication or therapy and administer it using the proper dose or regimen. Personalized medicine is being advanced through data from the Human Genome Project.

Phage - a virus for which the natural host is a bacterial cell.

Pharmacogenomics - pharmacogenomics is a branch of pharmacology concerned with using DNA and amino acid sequence data to inform drug development and testing. An important application of pharmacogenomics is correlating individual genetic variation with drug responses.

Phenotype - a phenotype is an individual's observable traits, such as height, eye color, and blood type. The genetic contribution to the phenotype is called the genotype. Some traits are largely determined by the genotype, while other traits are largely determined by environmental factors.

Polymerase chain reaction (PCR) - a method for amplifying a DNA base sequence using a heat-stable polymerase and two 20-base primers, one complementary to the (+)-strand at one end of the sequence to be amplified and the other complementary to the (-)-strand at the other end. Because the newly synthesized DNA strands can subsequently serve as additional templates for the same primer sequences, successive rounds of primer annealing, strand elongation, and dissociation produce rapid and highly specific amplification of the desired sequence. PCR also can be used to detect the existence of the defined sequence in a DNA sample.

Polymorphism - Polymorphism involves one of two or more variants of a particular DNA sequence. The most common type of polymorphism involves variation at a single base pair. Polymorphisms can also be much larger in size and involve long stretches of DNA. Called a single nucleotide polymorphism, or SNP (pronounced snip), scientists are studying how SNPs in the human genome

correlate with disease, drug response, and other phenotypes. Genetic variations occurring in more than 1% of a population would be considered useful polymorphisms for genetic linkage analysis. Compare mutation.

Predisposition - intrinsic likelihood of developing a particular disorder.

Primer - short pre-existing polynucleotide chain to which new deoxyribonucleotides can be added by DNA polymerase.

Probe - a probe is a single-stranded sequence of DNA or RNA used to search for its complementary sequence in a sample genome. The probe is placed into contact with the sample under conditions that allow the probe sequence to hybridize with its complementary sequence. The probe is labeled with a radioactive or chemical tag that allows its binding to be visualized. In a similar way, labeled antibodies are used to probe a sample for the presence of a specific protein.

Prokaryote - cell or organism lacking a membrane-bound, structurally discrete nucleus and other subcellular compartments. Bacteria are prokaryotes. Compare eukaryote. See chromosomes.

Promoter - a site on DNA to which RNA polymerase will bind and initiate transcription..

Protein - proteins are an important class of molecules found in all living cells. A protein is composed of one or more long chains of amino acids, the sequence of which corresponds to the DNA sequence of the gene that encodes it. Proteins play a variety of roles in the cell, including structural (cytoskeleton), mechanical (muscle), biochemical (enzymes), and cell signaling (hormones). Proteins are also an essential part of diet.

R

Recessive - recessive is a quality found in the relationship between two versions of a gene. Individuals receive one version of a gene, called an allele, from each parent. If the alleles are different, the dominant allele will be expressed, while the effect of the other allele, called recessive, is masked. In the case of a recessive genetic disorder, an individual must inherit two copies of the mutated allele in order for the disease to be present.

Recombination - the process by which progeny derive a combination of genes different from that of either parent. In higher organisms, this can occur by crossing over.

Restriction enzyme, endonuclease - a protein that recognises specific, short nucleotide sequences and cuts DNA at those sites. Bacteria contain over 400 such enzymes that recognise and cut over 100 different DNA sequences. See restriction enzyme cutting site.

Ribonucleic acid (RNA) - ribonucleic acid (RNA) is a molecule similar to DNA. Unlike DNA, RNA is single-stranded. An RNA strand has a backbone made of alternating sugar (ribose) and phosphate groups. Attached to each sugar is one of four bases--adenine (A), uracil (U), cytosine (C), or guanine (G). Different types of RNA exist in the cell: messenger RNA (mRNA), ribosomal RNA (rRNA), and transfer RNA (tRNA). More recently, some small RNAs have been found to be involved in regulating gene expression.

S

Sequence - see base sequence.

Sequencing - determination of the order of nucleotides (base sequences) in a DNA or RNA molecule or the order of amino acids in a protein.

Single Nucleotide Polymorphisms (SNP) - single nucleotide polymorphisms (SNPs) are a type of polymorphism involving variation of a single base pair. Scientists are studying how single nucleotide polymorphisms, or SNPs (pronounced "snips"), in the human genome correlate with disease, drug response, and other phenotypes.

Single-gene disorder - hereditary disorder caused by a mutant allele of a single gene (e.g., Duchenne muscular dystrophy, retinoblastoma, sickle cell disease). Compare polygenic disorders.

Stem cell - a stem cell is a cell with the potential to form many of the different cell types found in the body. When stem cells divide, they can form more stem cells or other cells that perform specialized functions. Embryonic stem cells have the potential to form a complete individual, whereas adult stem cells can only form certain types of specialized cells. Stem cells continue to divide as long as the individual remains alive.

Susceptibility - susceptibility is a condition of the body that increases the likelihood that the individual will develop a particular disease. Susceptibility is influenced by a combination of genetic and environmental factors.

T

Telomere - a telomere is the end of a chromosome. Telomeres are made of repetitive sequences of non-coding DNA that protect the chromosome from damage. Each time a cell divides, the telomeres become shorter. Eventually, the telomeres become so short that the cell can no longer divide.

Transcription - transcription is the process of making an RNA copy of a gene sequence. This copy, called a messenger RNA (mRNA) molecule, leaves the cell nucleus and enters the cytoplasm, where it directs the synthesis of the protein, which it encodes.

Translation - translation is the process of translating the sequence of a messenger RNA (mRNA) molecule to a sequence of amino acids during protein synthesis. The genetic code describes the relationship between the sequence of base pairs in a gene and the corresponding amino acid sequence that it encodes. In the cell cytoplasm, the ribosome reads the sequence of the mRNA in groups of three bases to assemble the protein.

V

Virus - a virus is an infectious agent that occupies a place near the boundary between the living and the nonliving. It is a particle much smaller than a bacterial cell, consisting of a small genome of either DNA or RNA surrounded by a protein coat. Viruses enter host cells and hijack the enzymes and

materials of the host cells to make more copies of themselves. Viruses cause a wide variety of diseases in plants and animals, including AIDS, measles, smallpox, and polio.

W

Western plot - Western blotting is a laboratory technique used to detect a specific protein in a blood or tissue sample. The method involves using gel electrophoresis to separate the sample's proteins. The separated proteins are transferred out of the gel to the surface of a membrane. The membrane is exposed to an antibody specific to the target protein. Binding of the antibody is detected using a radioactive or chemical tag. A Western blot is sometimes used to diagnose disease.

X

X Chromosone - the X chromosome is one of two sex chromosomes. Humans and most mammals have two sex chromosomes, the X and Y. Females have two X chromosomes in their cells, while males have X and Y chromosomes in their cells. Egg cells all contain an X chromosome, while sperm cells contain an X or a Y chromosome. This arrangement means that during fertilization, it is the male that determines the sex of the offspring.

Y

Y Chromosone - the Y chromosome is one of two sex chromosomes. Humans and other mammals have two sex chromosomes, the X and the Y. Females have two X chromosomes in their cells, while males have X and Y chromosomes in their cells. Egg cells contain an X chromosome, while sperm cells contain an X or a Y chromosome. This arrangement means that during fertilization, it is the male that determines the sex of the offspring.

ABBREVIATIONS

AAV;ANCA = Associated Vasculitis
ABPI = Association of the British Pharmaceutical Industry
ACR = American College of Rheumatology
ADA = Adalimumab
ADL = Activities of Daily Living
ADR = Adverse Drug Reaction
AE = Adverse Effects /Adverse Events
AIMS = Arthritis Impact Measurement Scale (also: AIMS2)
ANCA = Anti-Neutrophil Cytocplasmic Antibodies
anti-CCP/ACPA = Anti-Cyclic Citrullinated Protein antibodies
APLAR = Asia Pacific League of Associations for Rheumatology
ARA = American Rheumatism Association
ARUK = Arthritis Research, United Kingdom
AS = Ankylosing Spondylitis
ASAS = Assessment of SpondyloArthritis international Society (also: ASAS improvement and partial remission criteria)
ASDAS = Ankylosing Spondylitis Disease Activity Score
ASES = Arthritis Self-Efficacy Scale
AUC = Area Under the Curve
AVID:ANCA = Vasculitis Index of Damage
BASDAI = Bath Ankylosing Spondylitis Disease Activity Index
BASFI = Bath Ankylosing Spondylitis Functional Index
BASMI = Bath Ankylosing Spondylitis Metrology Index
BHPR = British Health Professionals in Rheumatology
BMA = British Medical Association
BMD = Bone Mineral Densitometry
BRAF = Bristol RA Fatigue Scale
BRC = Biomedical Research Centre
BRU = Biomedical Research Unit
BSA = Body Surface Area
BVAS = Birmingham Vasculitis Score
BVAS/WG = Birmingham Vasculitis Score for Wegener's Granulomatosis
CBT = Cognitive Behavioural Therapy
CCRN = Comprehensive Clinical Research Network
CDA = Combined Damage Assessment
CDAI = Clinical Disease Activity Index
CI = Confidence Interval
CI = Chief Investigator
CLRN = Comprehensive Local Research Networks
COMET = Core Outcome Measures for Effectiveness Trials
CPK = Creatine Phosphokinase
CPRD = Clinical Practice Research Datalink
CRF = Clinical Research Facility
CRF = Case Report Form
CRP = C-reactive protein
CTD = Connective Tissue Disease
CTU = Clinical Trials Unit
CVD = Cardiovascular disease
DAS = Disease Activity State (also: Das28; Das44)
DH = Department of Health
DIP = Distal Interphalangeal joint

ABBREVIATIONS

DLQI = Dermatology Quality of Life Measure
DM = Dermatomyositis
DMARD = Disease Modifying Anti-Rheumatic Drug
DMOAD = Disease Modifying Osteoarthritis Drugs
DQoL = Dermatology Quality of Life questionnaire
DUETS = UK Database of Uncertainties about the Effects of Treatments
EBM = Evidence Based Medicine
EMEA = European Medicines Agency
EMG = Electromyogram
EMG/NCS - = Electromyography (EMG) and Nerve Conduction Studies
ESR = Erythrocyte Sedimentation Rate
ETN = Etanercept
EudracCT = European Clinical Trials Database
EULAR = European League Against Rheumatism
EuroQol = Euro Quality of Life
EQ5D = Euro Qualtiy of Life descriptive system measure
FU = Follow up
GCA = Giant Cell Arteritis
GCP = Good Clinical Practice
GMC = General Medical Council
GP = General Practitioner
GTAC = Gene Therapy Advisory Committee
HAD = Hospital Anxiety Depression Scale
HAQ = Stanford Health Assessment Questionnaire
HES = Hospital Episode Statistics
HGC = Human Genetics Commission
HPA = Health Protection Agency
HRQoL = Health Related Quality of Life
HTA = Human Tissue Authority
i4i = Invention for Innovative Programme
ICC = Intra class Co-efficient
ICF WHO = International Classification of Functioning Disability and Health
Ig = Immunoglobulin
IIM = Idiopathic Inflammatory Myopathies
IL = Interleukin
IL-1 = Interleukin 1
ILAR = International League of Associations for Rheumatology
ILD = Interstitial Lung Disease
IMID = Immune Mediated Inflammatory Disease (*e.g. RA*)
IMP = Investigational Medicinal Product
INF = Infliximab
INVOLVE = National advisory group that supports greater public involvement in NHS, public health and social care research
IP = Intellectual Property
IPA = Interpretative Phenomenological Analysis
ISO = International Organization for Standardization
JIA = Juvenile Idiopathic Arthritis
JSN = Joint space narrowing score
JSW = Joint space and width measurement
LDAS = Low Disease Activity State
LMIC = Low and Middle Income Countries

ABBREVIATIONS

LOS = Longitudinal Observational Study
LFT = Liver Function Test
LR = Likelihood ratios
MAHSC = Manchester Academic Health Sciences Centre
MCID = Minimal Clinically Important Difference
MCII = Minimal Clinically Important Improvement
MCIS = Minimal Clinically Important State
MCP = Metacarpophalangeal (the bones in fingers)
MEI = Mander Enthesitis Index
MetS = Metabolic Syndrome
MFI = Multi-dimensional Fatigue Inventory
MHAQ = Modified Health Assessment Questionnaire (*see: HAQ*)
MHRA = Medicines and Healthcare products Regulatory Agency
MINAP = Myocardial Ischaemia National Audit Project
MMPs = Matrix Metalloproteinase
MRC = Manchester Research Council
MRC HRA = MRC Health research Authority i4i Invention for Innovation RCT
MRI = Magnetic Resonance Imaging
MS = Musculoskeletal disorders
MTP = Metatarsal-phalangeal
MTX = Methotrexate
NCS = Nerve Conduction Study
NHS = National Health Service, United Kingdom
NICE = National Institute for Health and Care Excellence (UK)
NIHR = National Institute for Health Research
NPV = Negative predictive values
NRAS = National Rheumatoid Arthritis Society
NRES = National Research Ethics Services
NSAID = Non Steroid Anti Inflammatory Drugs
OA = Osteoarthritis
OARSI = Osteoarthritis Research Society International
ONS = Office for National Statistics
OT = Occupational Therapy
PASI score = Psoriasis Area Severity Index
PASI = Patient Specific Index
PASS = Patient Acceptable Symptomatic State
PBMC = Peripheral blood mononuclear cell
PE = Public Engagement
PF = Physical Functioning
PGA = Physician Global Assessment
PGA = Psoriasis Global Assessment
PhGA = Physician Global Assessment
PI = Principal Investigator
PI = Proximal Interphalangeal
PIAG = Patient Information Advisory Group
PM = Polymyositis
PMN = Polymorphonuclear
PMR = Polymyalgia Rheumatica
PMR-AS = Polymyalgia Rheumatica Activity Score
PPI = Patient and Public Involvement
PPV = Positive predictive values

ABBREVIATIONS

PRO = Patient Reported Outcome
PsA = Psoriatic Arthritis
PsARC = Psoriatic Arthritis Response Criteria
PT = Physio-Therapy / Physical Therapy
PtGA = Patient Glogal Assessment
QALYs = Quality-Adjusted Life-Years
RA = Rheumatoid Arthritis
RADAI = Rheumatoid Arthritis disease activity index
RAI = Ritchie Articular Index
RCT = Randomized Controlled Trial
RF = Rheumatoid Factor
RfPB = Research for Patient Benefit Programme
ROC = Receiver Operative Curve
RUG = Research User Group
SA = Spondylitis Ankylopoetica
SAE = Serious Adverse Events
SD = Standard Deviation
SDAI = Simplified Disease Activity Index
SDC = Smallest Detectable Change
SDD = Smallest Detectable Difference
SEM = Standard Error of the Mean
SES = Standardized Effect Size
SF = Synovial Fluid
SF-36 = Medical Outcome Study Short Form
SIJ = Sacroiliac Joint
SJC = Swollen Joint Count
SLE = Systemic Lupus Erythematosis
SLEDAI = Systemic Lupus Erythematosis Disease Activity Index
SM = Synovial Membrane
SNP = Single Nucleotide Polymorphisms
SOP = Standard Operating Procedure
SpA = Spondyloarthritis
SRM = Standardized Response Mean
SS = Sjögrens Syndrome
SSc = Systemic Scleroderma
SSAR = Serious Suspected Adverse Reaction
SSZ = Sulfasalazine
SUSAR = Suspected Unexpected Serious Adverse Reaction
TJC = Tender Joint Count
TNF = Tumour Necrosis Factor
TSC = Trial Steering Committee
UKRAG = UK Rheumatoid Arthritis Genetics Consortium
UoM = University of Manchester
US = Ultrasound
VAS = Visual Analogue Scale
WHO = World Health Organization
WOMAC = Western Ontario and McMaster Universities Osteoarthritis Index

INFORMATION SOURCES

http://www.invo.org.uk/resource-centre/useful-information/

http://www.northwestpeopleinresearchforum.org/resource/jargon-buster/

http://www.nihr.ac.uk/Pages/Glossary.aspx

http://www.omeract.org/pdf/OMERACT11%20Glossary.pdf

http://www.genome.gov/glossary/

http://www.geneticalliance.org.uk/glossary.htm

http://www.geneticseducation.nhs.uk/genetics-glossary

http://www.bu.edu/enact/programs-and-resources/arthritis-glossary/

http://www.arthritisresearchuk.org/arthritis-information/inflammatory-arthritis-pathway/glossary.aspx

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