Jargon Buster 2016

Word, acronym or phrase	In full	Explanation	Category	Further help
Abstract	-	A short summary of a piece of research, usually seen at the start of a journal article to give an idea of what the contents include (like the back cover of a book)	Research term	
ADR	Adverse Drug Reaction	Any side-effect of taking a drug (usually negative) e.g. rashes, mood change.	Clinical research	https://cks.nice.org.uk/adverse-drug-reactions#!topicsummary
ADE	Adverse Drug Event	Any side effect or 'event' that happens while someone is taking a drug – but that may not be related to the drug (e.g. taking paracetamol and then falling and breaking a hip are probably not related). An ADR is a special sub-set of ADEs, where a clear relationship has been established between taking a drug and a side effect (e.g. taking insulin and the blood sugar level falling).	Clinical research	http://www.rds-london.nihr.ac.uk/RDSLondon/media/RDSContent/files/PDFs/RDS_PPI-Handbook_web_1.pdf Most clinical research terms can be found in the RDS handbook, at the back.
Advisory group	-	A research project or an organisation often brings together experts in several different fields to provide advice about their specific area of expertise during the project development or over the course of several years of conducting research. PenPIG, for example, is an advisory group for the PenCLAHRC	Research term; PPI term	
AHSN	Academic Health Science Network	AHSNs are organisations, like PenCLAHRC, that work across boundaries and bring together NHS organisations, researchers,	Organisation	Our local AHSN: www.swahsn.com

		charities, local authorities and industry to support the implementation of healthcare research into practice as rapidly as possible, with a view of improving outcomes for patients.		The national network of all 15 AHSN: http://www.ahsnnetwork.com/about-academic-health-science-networks/
Arm	-	In a traditional clinical trial, participants are (usually randomly) assigned to an 'arm' of the trial. In one arm, they may be given the new drug being tested, while the other arm are given a neutral, non-medicinal alternative called a 'placebo'. In this way the effects of the new medication can be simultaneously tested 'against' the placebo to see if there is any effect.	Clinical research	
Applied Research	-	Research that is done to solve a distinct problem, or to test something in the 'real world' that has worked 'in the lab' or in theory, or to answer a very specific question in real life (see also Basic research – that aims to explore an interesting area and devise theory)	Research term	
Analysis (data analysis)	-	The process of taking the 'raw data' that has been collected during research and cleaning it, running any modelling or statistical tests and turning it into usable 'evidence' where patterns can be found, conclusions suggested and that can be used as a basis to support decisions.	Research term	
Baseline, Baseline data	-	Data that is generally gathered at the very start of a project or clinical trial before any	Research term, Clinical research	

		intervention starts, so that the researchers can see what impact the intervention has. For example, in a clinical trial, baseline data might include age, height, weight and some measure of the condition or injury that the trial aims to improve.		
Basic research	Also known as ‘lab-based’ or ‘bench’ research (sometimes ‘pure’ or fundamental’ research)	Basic research is where all new ideas start, new theories are formed and predictions are made. It doesn’t always have a clear ‘use’ – for example, computers today are based on research done in mathematics in the 1800’s, but which had no real use at the time. In healthcare, basic research is often that carried out in laboratories	Research term	
Bias		Bias describes anything that distorts or affects a study in a way that would alter the findings. It may relate to a number of different elements such as the researchers opinion or how they chose the research participants.	Research term	
Blinded, Blinding		As patients are recruited to a clinical trial, there will be an individual who assigns them to one ‘arm’ of a trial to receive treatment or not. Blinding is the term used to describe whether the subjects of the research know whether they are receiving the treatment or the placebo or not. If the clinicians do not know either, then this is called double blinding.	Clinical research	

Carer	-	A carer is someone who looks after another person because that person needs support with everyday activities such as getting out of bed, cooking, washing themselves or dressing. Often carers are family members – even children -– and unacknowledged for the care that they provide, but are essential to the person they look after and the NHS in general.	Patient-related	CarersUK is a major charity raising awareness of carers and providing support and advice: http://www.carersuk.org/
Case study	-	Usually refers to an in-depth study or description of one or more patients, groups of patients or elements of data to provide a details picture of a situation	Research term, clinical research	
CCG	Clinical Commissioning Group	A new law was passed in 2013 that created CCGs as “clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.” They are led usually by GPs and are legally responsible for making services available to people (‘commissioning’ services) in their area. There are now 209 CCGs in England.	Organisation	http://www.nhscc.org/ccgs/ https://www.kingsfund.org.uk/projects/new-nhs/clinical-commissioning-groups
Citation		Broadly speaking, a citation is a reference to a published journal article that has been used as the basis of evidence for an argument made in text. Often they appear in Journal articles within the text like so (Burchmore, 2016) and then the article referred to is listed at the end in a Bibliography.	Research-related	

CLAHRC	Collaboration for Leadership in Applied Health Research and Care	There are currently 13 Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) are funded by the National Institute for Health Research and undertake high-quality applied health research focused on the needs of patients and support the translation of research evidence into practice in the NHS. CLAHRCs are collaborative partnerships between a university and the surrounding NHS organisations, focused on improving patient outcomes through the conduct and application of applied health research. They create and embed approaches to research and its dissemination that are specifically designed to take account of the way that health care is increasingly delivered across sectors and a wide geographical area.	Organisation	National CLAHRC website: http://www.clahrcprojects.co.uk/ PenCLAHRC website: http://clahrc-peninsula.nihr.ac.uk/
Clinical research	-	Research that looks at health and illness in humans. It is often is done in a clinical setting (such as a hospital or through a GP surgery), and determines the safety and effectiveness (efficacy) of medications, devices, diagnostic products and treatment regimens intended for human use. These may be used for prevention, treatment, diagnosis or for relieving symptoms of a disease.	Research-related	
CRN	Clinical Research Network	The CRN is also funded by the NIHR (like PenCLAHRC) and tries to make it possible for	Organisation	National CRN website: http://www.nihr.ac.uk/nihr-in-

		patients and health professionals across England to participate in clinical research studies within the NHS. The CRN provides the infrastructure that allows high-quality clinical research funded by charities, research funders and life-sciences industry to be undertaken throughout the NHS. They work with patients and the public to make sure their needs are placed at the heart of all research, and providing opportunities for patients to gain earlier access to new and better treatments through research participation.		your-area/local-clinical-research-networks.htm Our local CRN (South West Peninsula): http://www.nihr.ac.uk/nihr-in-your-area/south-west-peninsula/
Clinical practice research data (CPRD)	-	The UK is the only country in the world where data has been recorded, since the 1940s, for every person registered with the health service – from birth to death. This means there's a huge amount of data that researchers can learn from to help save lives. The records of your health, lifestyle and health habits (your data) already make a huge contribution to research, just by providing statistics about illness in the UK. Researchers are able to access huge databases of anonymised data about patients in the UK so that they can look at trends and patterns without having to recruit patients.	Research-related	Find out more about the database here: https://www.cprd.com/intro.asp
Clinical trial (RCT)	Randomised Controlled Trial	A structured way of investigating whether a medicine or device has a measureable effect on patients ('clinical efficacy') in the way that	Research-related	The UK CTU Network has produced this helpful booklet explaining clinical trials:

		is desired and is safe to use or only has side-effects that can be easily handled ('clinical safety'). There are many different ways of running a clinical trial, but the most common is the RCT, where patients are recruited and then randomly assigned to 'arms' in the trial. One arm will get the intervention and the other will get either a neutral 'placebo' or 'best current care'. The effect on patients in the two arms is then compared and analysed to see how effective the intervention has been.		http://c.ymcdn.com/sites/www.ukcrc-ctu.org.uk/resource/resmgr/2)_understanding_clinical_tr.pdf
CTU	Clinical Trials Unit	Clinical Trials Units (CTUs) are specialist units which have been set up with a specific remit to design, conduct, analyse and publish clinical trials and other well-designed research. They have the capability to provide specialist expert advice and coordination to undertake successful clinical trials. In addition, most CTUs will have expertise in the coordination of trials involving medicines - which must be conducted in compliance with UK Regulations and EU Directives for Clinical Trials.	Organisation; Research-related; clinical research	The national CTU Network: http://www.ukcrc-ctu.org.uk/ Our local NIHR Exeter CTU: https://ctu.exeter.ac.uk/web/
Co-production	-	Co-production is a slippery concept to define, and in fact defining what people think it is can be a useful place to start any co-production work! Essentially it is a term to describe the methods and practices of getting service users, patients, the public,	Research term; PPI term	The Social Care Institute for Excellence has a very good introduction to Co-production: http://www.scie.org.uk/publications/guides/guide51/index.asp

		carers, clinical staff, management – everyone involved in running or using a service (usually) – together to decide what they need and how to achieve it. Everyone should be seen as equal and any decision made should be arrived at jointly.		
Commissioner, commissioning	-	An officer (or organisation) that 'commissions' health or social care services from another organisation (or individual). For example, a CCG may 'commission' a hospital to provide a diabetic clinic for outpatients so that the GP practices that the CCG oversee can send their diabetic patients to that clinic.	Organisation	NHS England's definition of Commissioning and a useful infographic about the situation nationally: http://www.nhs.uk/NHSEngland/thenhs/about/Documents/Commissioning-FINAL-2015.pdf
Confidentiality	-	Often taking part in a clinical trial will involve a patient giving a lot of information to the people running the trial. A Confidentiality agreement is usually set in place to reassure them that this data will be protected, not shared with anyone and in some cases even anonymised so no one knows who it belongs to. There will be a legal agreement to protect confidential information revealed during discussions or negotiations with another party. It applies to both organisations and individuals and is likely to contain clauses covering protection of people against the copying or retention of confidential information, disclosing information that is not already in the public domain to a third	Research-related	

		party and remedy for a breach of the agreement.		
Consultation	-	In everyday language, this is the planned session one might have with a consultant at the hospital about a condition they are caring for. It can also be used as a research method, where a project team gather a small group of lay people and share their research results with them to get a second opinion (or run a national survey etc). It is NOT involvement, but a useful way of finding out the general opinion of a group of people.	Clinical; research-related	
Control / controls / control arm	-	In a classic clinical trial, patients will be assigned to an intervention (treatment arm) or to receive a placebo or current best treatment (control arm). The patients in the control group do not receive the new medicine/treatment/device and so will not show the effect of the new treatments. They can then be used as a comparison to those patients that DID receive treatment – it is assumed that any difference between the two groups will be an effect of the treatment.	Clinical research	
CQC	Care Quality Commission	The independent Regulator for health and social care services in the UK. They monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety and then publish what they find, including performance ratings to help people choose care.	Organisation	The Care Quality Commission's website: https://www.cqc.org.uk/

CRN	Clinical Research Network	The UK Clinical Research Network makes it possible for patients and health professionals across England to participate in clinical research studies within the NHS. The CRN provides the infrastructure that allows high-quality clinical research funded by charities, research funders and life-sciences industry to be undertaken throughout the NHS. They work with patients and the public to make sure their needs are placed at the heart of all research, and providing opportunities for patients to gain earlier access to new and better treatments through research participation.	Organisation	The national Clinical Research Network: http://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/crn/ And our local NIHR Clinical Research Network South West Peninsula: http://www.nihr.ac.uk/nihr-in-your-area/south-west-peninsula/
Data	-	Simply – bits of information gathered during any kind of research! Data can be the words said during a single interview with a patient; they can be the measurements taken on your 'FitBit', they could be the observations made by a nurse of a patient during an operation. When brought together and analysed, data becomes evidence.	Research term	
Data analysis	-	Any process or method by which individual bits of data are made useful by combining them with other bits of data, analysing one bit of data against another etc.	Research term	
Data protection	-	This is about how data that has been collected through research (etc) - or created through data analysis – can be kept safe, either as a dignital file or a physical 'thing'.	-	The UK Data Protection Act 1998: https://www.gov.uk/data-

		Most commonly this phrase – data protection – will be in the context of the Data Protection Act 1998 ('DPA') which makes it a legal requirement for anyone collecting information about an individual to guarantee to that individual certain things (such as your data will be kept safe, it will not be shared without your knowledge, it will be destroyed after a certain period, it will be used in these ways etc).		protection/the-data-protection-act
Dissemination	-	This is usually seen as an umbrella term for 'spreading the word' about research to a wider audience. It can include researchers running training courses for clinicians, writing articles for Journals, supporting patients to speak on radio programmes or to create artwork that become posters. Anything that spreads news about the research is 'dissemination' and it is important that patients are involved as often they have very different audiences than clinicians ('Grass roots'). There is a move afoot to see more dissemination of practices (implementation) rather than just 'news'.	Research term; clinical research; PPI term	
Empowerment	-	Methods and processes by which the capacity of individuals, groups and/or communities to take control of their circumstances, exercise power and achieve their own goals, and the process by which, individually and collectively, they are able to	PPI term	

		help themselves and others to maximize the quality of their lives		
Ethics	-	The name given to the code of practice based on a set of decent, fair and moral principles and guidelines that researchers should abide by. Research that will seek to gain personal confidential information or to test a new intervention on people must get ethical approval from an Ethics Research Committee (REC).	Research term; clinical research	
Ethics committee	Also: Research ethics committee, REC	A committee of academics, clinicians and interested lay people who between them review research proposals to ensure that the researchers plan to ‘do no harm’, and have considered scenarios where things could go wrong (and how to deal with that) in order to protect potential recruited participants.	Research term	
Evaluation	-	A way of systematically determining a subject’s merit, significance or worth, often testing it against a set of standards. In research, evaluation is often carried out to see if a new process is working in practice, or seeing which of a set of alternatives is better suited to a situation.	Research related	
Evidence	-	Anything presented to support an argument! All research aims to gather data that is collected by robust methods and analysed well in order to build a suit of linked data that answers a question – the data used to	Research related	

		answer the question is generally called ‘evidence’.		
Evidence base	-	The suite of data that has been gathered and analysed to a high standard in order to build a strong data-set to ‘prove’ an answer is right or that a process has worked. This can also include reference to ‘the literature’ as well as gathered data.	Research related	
Evidence-based medicine (EBM)		We firmly believe nowadays that better health care can be provided to patients by making decisions that are based on evidence. All healthcare professionals – and interested members of the public – can support this by finding and using evidence to make effective health and social care decisions. This is often led by systematic reviews, which gather together everything that has been published on a topic to find the pattern of ‘what works’ and so find the best thing to do in a situation.	Research related; clinical research	
Experimental research	-	In experimental research, there are certain steps that researchers take, the first one being an effort to control some variables, which can be controlled, and then systematically manipulating other variables. The purpose of using control and manipulation on the variables of the experiment is to see if the variables that are being manipulated have an effect on the results, or data. This way, scientists can text	Research related; clinical research	

		hypothesis and analyze outcomes to make new inferences from the research.		
Experts-by-experience		In healthcare research, this refers to anyone who has had experience of living with a condition, or of using a service and is using their experience as input to a research project. The experience they have makes them an expert in what it is like to live with that condition or to use that service – a perspective that can be very useful to people without that experience.	Research related; PPI term	
Focus group	-	A research technique used for gathering qualitative data. Focus groups can be used to elicit the views of a group (usually around six to ten individuals) that have common experiences or interests. They are brought together with the purpose of discussing a particular subject, under the guidance of a facilitator. They are a bit more formal than a 'workshop'.	Research term; PPI term	
Grey literature	-	This is material that has not been published through the usual 'academic channels' such as established Journals or presented at conferences. This could be PhD theses, talks given internally to other groups, or published on a website only, and can be an important – but hard to find – source of information!	Research term	
Health Education England	HEE	Health Education England is – like Public Health England – an 'executive agency' of the Department of Health that works across	Organisation	https://hee.nhs.uk/

		England to deliver high quality education and training for a better health and healthcare workforce. They oversee the standards for training for doctors, nurses and a host of other allied professions (together with the 'Colleges' for various professions), research new ways of training and new content, and keeping an eye on where gaps are in terms of locations or types of workers.		
HealthWatch	-	HealthWatch England was set up as an independent UK national consumer champion in health and care. They ensure the voice of the consumer is heard by those who commission, deliver and regulate health and care services. More local HealthWatches are actually different organisations – only HealthWatch UK is legally specified in the Health and Social Care Act; local HealthWatches tend to be Community-interest Companies or run by local district or county councils etc – but all have a duty to be 'the voice of local people'.	Organisation	http://www.healthwatch.co.uk/
HTA	Health Technology Assessment/Appraisal	This can refer to several things: 1. The NIHR HTA is a funding programme, funding research about research about the effectiveness, costs and broader impact of healthcare treatments and tests for those who plan, provide or receive care in the NHS. 2. HTA can also refer to Health Technology Assessment – a process by which evidence and data about a new medicine	Research related; clinical research	NIHR HTA funding programme: http://www.nets.nihr.ac.uk/programmes/hta Our own local HTA (Assessment) team: PenTAG: http://medicine.exeter.ac.uk/esmi/workstreams/pentaghealthtechnologyassessment/

		or device is thoroughly 'assessed' by an independent evaluator before it goes to NICE, who may then licence it for use in the NHS. 3. The process by which NICE licences a new medicine or device is also called Health Technology Appraisal, which includes looking at the Assessment, listening to clinicians and patients and then a Committee making a decision. 4. Human Tissue Authority, who controls the use of human tissue (dead or alive) in research and medicine.		NICE's HTA process: https://www.nice.org.uk/About/What-we-do/Our-Programmes/NICE-guidance/NICE-technology-appraisal-guidance Human Tissue Authority: https://www.hta.gov.uk/
IHR	Institute of Health Research	The Institute for Health Research, like PenCLAHRC itself, sits within the Medical School at Exeter University. There is some overlap in staff and work between the IHR and the CLAHRC, but while the CLAHRC actively works outside of the University (such as with projects in Plymouth), the IHR focusses only on work being carried out in the Medical School.	Organisation	The IHR webpages in the Medical School website: http://medicine.exeter.ac.uk/research/healthresearch/
Implementation		The process of putting into practice something that has been discovered by research. Often seen as the last thing to do in a research project, it is now being given the same importance as PPI, and new ways of smoothly implementing into practice the benefits of research that is carried out is	Research related	Our own PenCLAHRC Implementation Science team: http://clahrc-peninsula.nihr.ac.uk/implementation-science

		becoming a growing area of healthcare research.		
Intervention	-	In medicine, an intervention is an action which changes the outcome or course of a condition or disease so as to prevent harm or improve health through the use of treatments, medicinal products, medical devices or procedures/surgery.	Clinical research	
Interview	-	In research generally, interviews are used as a key qualitative data collection method. They can be highly structured (where the interviewer has a list of questions that they want answers to, often prompted by reading the literature on the topic) or semi-structured (where the interviewer has specific questions, but allows the person they are talking to some freedom to talk more widely). Essentially, an interview is a conversation about a topic that is somehow recorded so it can be used as data in research.	Research term	
Involvement	-	The process of being involved!	PPI term	
INVOLVE	-	INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research. Its role is to support active public involvement in NHS, public health and social care research. It is one of the few government funded programmes of its kind in the world. As a national advisory group	Organisation	http://www.invo.org.uk/ - the INVOLVE website

		their role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.		
Journal	-	Most academics will want to share their work with other academics, and this is generally done through either conference presentations or publishing an article in a Journal. Most research disciplines have a range of Journals, with some being well-regarded (for example in healthcare, The Lancet and the British Medical Journal (BMJ)) and others less so. Journals have their own individual rules about the quality of data and evidence they accept, how well written a paper must be etc, and once your work is published in a Journal it is considered to be ‘out there’. Usually, each piece of work submitted to a Journal is also peer-reviewed to see what other people think of it (and what might need to be improved before publication). If work is not published, it doesn’t have the same power and validity.	Research term	
Journal article	-	A single report on a piece of work published in a peer-reviewed Journal.	Research related	
Lay	Also: lay person, lay perspective	Originally a term used in the church to describe anyone who had not taken formal	PPI term, clinical research	

		vows to be a priest or monk! Nowadays it usually refers to someone who has not had the formal training to do a specific job, so anyone involved in healthcare who is not medically trained could be – from a clinician's point of view – a lay person. The term also implies that the lay person 'lacks understanding' of a topic, which is why the use of 'expert-by-experience' has taken off as a term, to show that although lay people do not have trained medical expertise in medicine, they are experts in their own health and conditions.		
Lay language	-	As well as being written in Plain English, research documentation should be written in lay language – that is, with no acronyms, no medical terms, and no jargon and with complex ideas explained simply. See also Plain English.	PPI terms; research terms	
Lay summary	-	See also Plain English Summary – this is a summary of a piece of research that is either planned or being reported on. The summary should be in Plain English, but also lay language i.e. no jargon, no long words, no technical terms and easy to read.	PPI, Research	
Lived experience	-	Personal knowledge about a subject gained by direct, first-hand experience of that subject – such as the lived experience of having a condition. Living with it every day gives a lay person an expertise in that	PPI	

		condition which is equivalent to a clinicians expertise in that topic, but based on 'living with it' rather than 'what causes it, how do I cure it etc'. See also 'Expert-by-experience'		
Methodology	-	The systematic use of specific methods to gather and analyse data during research – many methods may be used (e.g. interviews, surveys, observations etc) and together they are the 'methodology' for that piece of work. Sometimes different 'disciplines' use different methodologies entirely – for example, an engineer researching a new design of crutches would probably start off wanting to use different research methods to a PPI person – so you would say that their methodologies differ.	Research term.	
MONITOR	-	Monitor used to be the independent regulator that oversaw the performance, safety and finances of all Foundation Trust hospitals. In 2016, it was merged with other organisations into "NHS Improvement" that now has a remit to ensure that the NHS can meet the current challenges it faces.	Organisation	https://improvement.nhs.uk/
NHS	National Health Service	Unlike some countries, we have a 'National' healthcare system, where the population pay taxes and National Insurance, out of which pot the Government sets some aside to look after the population's health. In the UK, the 'state-funded healthcare system' can be used by anyone who is a UK resident, free of	Organisation	

		charge at the point of delivery (we do not pay the doctor for our healthcare, but instead we pay national insurance when we work). In other countries, healthcare might be provided by a healthcare system, but paid for by the individuals needing care – people in these countries usually have health insurance, and it is this that pays for their care.		
NHS England	NHSE	After the Health and Social Care Act in 2013, NHS England became the organisation that effectively 'runs the NHS'. They set the priorities and direction of the NHS and encourage and inform the national debate to improve health and care. They commission some services at a national level (such as offender health, healthcare for the Forces, some highly specialised services), oversee the performance of the 'healthcare system' and distribute money from the Department of Health to CCGs, hospitals etc.	Organisation	NHS England: https://www.england.nhs.uk/
NICE	National Institute for Health and Care Excellence	The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care. They provide Guidelines of 'best care' for conditions and licence and approve drugs, devices and treatments for use in the NHS.	Organisation	National Institute for Health and Care Excellence: www.nice.org.uk
NIHR	National Institute of Health Research	The NIHR is the NHS led organisation that governs and fund all NHS research – the 'research arm' of the NHS. It exists to make sure that high-quality research is carried to	Organisation	http://www.nihr.ac.uk/

		and that it quickly becomes good practice across the country in a consistent way nationally.		
Outcome	-	What is being looked for in research – e.g. pain is reduced or a cure is found. See also PROMS	Research term; clinical research	
Participant	-	Someone taking part in research as a source of data, either as a patient receiving treatment or perhaps being interviewed about their experience of care etc. In 'PPI terms', this is not seen as 'involvement' as the participant has little opportunity to change the direction of research or to make it better for other participants.	Research term; clinical research; PPI term	
Participatory research	Also known as 'Participatory Action Research'	A specific type of research where researchers and 'a community' work together as equals to identify and research a problem and come up with a solution that works for that group in that context. Key ideas are collaboration – no one has more 'right' than anyone else; a cyclical research method, where gathering data and analysing it then suggests further data to be collected and analysed, and everyone equally being active in their participation – no one gets to sit and just watch. Importantly, the solution grows out of the conversations that the participants have and the data that they gather, rather than being specified by researchers or at the start of the process.	Research term; PPI term	A link to an article outlining what participatory action research looks like in healthcare research: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2566051/

Patient information sheet	PIS	In a clinical trial, this is the document, produced to high standards and according to strict guidelines, that tells a potential patient all about the research that they are about to volunteer to be part of. It must include certain things such as contact details, evidence that the research has been approved by an ethics committee, details of exactly what processes, tests, medicines or treatments will be involved, what the anticipated outcomes will be, what side-effects there might be and so on. It must be handed to a potential recruit in plenty of time to allow them to read it and ask questions before they sign the consent form, agreeing to take part.	Clinical research	The Health Research Authority has more information about the standards for information sheets and consent forms: http://www.hra.nhs.uk/resources/before-you-apply/consent-and-participation/consent-and-participant-information/
Patient information leaflet	PIL	A Patient Information Leaflet is the information sheet in a box of medicine that you might find in a pharmacy, with side effects, dose instructions, manufacturers details etc. Again, there are very strict international standards defining what information a PIL must contain.	Patient related	The Medicines and Healthcare Products Regulatory Agency (MHRA) has a site with more information: http://www.mhra.gov.uk/spc-pil/
Patient representative		A patient who has volunteered or been selected to represent a wider group of patients – for example PenPIG are often representing the ‘patients of the South West Peninsula’ or patients with the same conditions that they have.	Healthcare research’ PPI term	

Peer review		A form of academic regulation, whereby the work of one person is reviewed by others of similar or higher rank, expertise etc. Peer review is now a standard step in publishing a journal article, and there is also a lot of informal peer-review in medicine and research generally.	Research term	
PenCLAHRC	Collaboration for Leadership in Applied Health Research and Care, South West Peninsula	PenCLAHRC is one of 13 CLAHRC across the UK, all with a slightly different focus. We are a partnership of NHS Trusts across Devon, Cornwall and Somerset, plus the Universities of Exeter and Plymouth. We have three key objectives: 1. To increase the volume and quality of patient-focused research in the South West 2. To improve health outcomes by more effective use of evidence to drive health services 3. To increase capacity within the health economy to use and generate evidence	Organisation	http://clahrc-peninsula.nihr.ac.uk/ A flyer with some more information on PenCLAHRC that you can download and share: http://clahrc-peninsula.nihr.ac.uk/uploads/attachments/2016UEMS063%20PenCLAHRC%20Flyer%20v8.pdf
PenPIG	PenCLAHRC's Patient Involvement Group	A group of patients and public members who act as critical friends to the PenCLAHRC, reporting to the Management Board and assisting researchers in making healthcare research more 'grounded' in the reality of patient experiences.	Organisation; PPI terms	The *NEW* PenPIG webpage: http://clahrc-peninsula.nihr.ac.uk/meet-penpig
Placebo	-	An inactive (dummy) treatment often given to controls in trials. The placebo is delivered in a form, which is apparently identical to the active treatment being tested in the trial, in	Clinical research	

		order to eliminate psychological effects on the outcome.		
Plain English	-	Plain English should be clear, not use long or technical words or jargon, and written in short, easy-to-read sentences. The concept grew out of a campaign to improve Government and banking information in the 1990's, which was often unreadable by ordinary people! See also 'Lay language'.		The Plain English campaign website: http://www.plainenglish.co.uk/
Plain English summary	PLS	A summary of a research proposal that sets out in clear language (both plain English and lay-friendly language!) what the research project is all about. Writing a PLS is now pretty much compulsory for getting funding, and is also a very common way for patients and the public to get started in PPI.	Research term; PPI term	
PI	Principle Investigator	Although most research is carried out by teams of researchers, there is always one person who is given the responsibility of being 'in charge' of the project. From a funding point of view, they have legal responsibility to make sure the funds are spent well and appropriately. They are also generally the most senior academic in the team and have a duty to make sure everyone is carrying out the research well.	Research term	
PPI	Public and Patient Involvement	You should all have your own definitions of this! But INVOLVE defines PPI as: research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for'	Research term; PPI term	INVOLVE: http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/

		them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.		
PROM	Patient Reported Outcome Measures	Generally speaking, ‘Patient-reported Outcome Measures’ are a way of measuring the effect of treatment in a standard way (usually a survey or some kind of numerical scale) or otherwise gathering information directly from patients about their symptoms, condition and overall quality of life. For example, the NHS has a national PROM tool for anyone who has had a knee replacement, so that it can gather data on where knee ops go well and where improvement might need to be made. Sometimes research is carried out with patients to try and define a new PROM, but this is not easy – a PROM needs to be simple to answer but still reveal real change in that patient, and do the same for any other patient using the same tool so that results can be compared	Research term; clinical research; patient-related	A PDF from Scottish Healthcare Improvements explains a lot more about PROMS: http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=15&cad=rja&uact=8&ved=0ahUKEwiJ4taQ6svRAhVhCsAKHdt3Dp8QFgh5MA4&url=http%3A%2F%2Fhealthcareimprovementscotland.org%2Fhis%2Fidoc.ashx%3Fdocid%3D595f3ffe-c11d-4023-b253-7ae90d629f3b%26version%3D-1&usg=AFQjCNHzDM4fHEmUlFZuXCfatc1uBulLnQ&sig2=C_ie3UY-uEylOilgfI7d0A
Protocol	-	The written, pre-defined procedures to be carried out in research, usually a clinical trial or systematic review. In clinical trials, a protocol makes sure that every patient recruited to the trial is treated exactly the same, to remove any variables or bias. In a	Research term; clinical research	

		systematic review, a protocol means that all journal articles are treated the same way to eliminate bias.		
Public Health England	PHE	Public Health England is an 'executive agency' of the Department of Health, aiming to protect and improve the nation's health and wellbeing, and reduce health inequalities. They are responsible for national health campaigns (such as Change4Life), screening (such as for prostate or cervical cancer), collecting and analysing data on cancer or new viruses and providing immunisations (such as for health workers or babies), alongside national 'health security'.	Organisation	https://www.gov.uk/government/organisations/public-health-england
Public health research		This is research that is directed towards having an impact on the health of a population, and reducing 'health inequalities', rather than just those people with a single condition for example.	Research term	
Qualitative (Quali)	-	Anything relating to qualitative data or the methods used to collect it and analyse it. 'Qualitative' refers to 'qualities', such as 'patient experience'.	Research term	
Qualitative data	-	Any data that is largely made up of words instead of numbers. Qualitative data tells us about how someone experiences their world, how something made them feel, how much 'better' one treatment is than another etc.	Research term	
Qualitative research	-	Research carried out to collect qualitative data, using qualitative methods such as interviews, observations, focus groups and	Research term	

		workshops. Quali data is better for describing human behaviour from the perspective of the people involved, or for finding out what motivates people for example.		
Quantitative (Quant)	-	Anything relating to quantitative data or methods – essentially ‘quantitative’ refers to ‘quantities’ or numbers.	Research term	
Quantitative data	-	This is data that mostly involves numbers and numerical information – weight, height and BMI of patients, how often a service is used, how much improvement someone has made (often collected using a survey) etc. It measures how often something happens, the size of the effect, and – by using statistical methods – can help us to find patterns between health and behaviour.	Research term	
Quantitative research	-	Any research that relies more on the collection and analysis of numbers than words. Usually uses ‘quantitative methods’ such as surveys and questionnaires to collect information, which may then be analysed using mathematical or statistical methods.	Research term	
Questionnaire	-	Usually a set of printed, written or online questions with a choice of answers, devised for the purposes of collecting data in a systematic way from (usually) a large group of people. May also be called a survey.	Research term	
RCT	Randomised controlled trial	A research trial in which subjects are randomly assigned to two groups: one (the experimental group) receiving the	Research term	

		intervention that is being tested, and the other (the comparison group or controls) receiving no treatment or a conventional treatment. The two groups are then followed up to see if any differences between them result. This helps people assess the effectiveness of the intervention.		
RDS	Research Design Service	The National Institute for Health Research (NIHR) funds the Research Design Service (RDS) to provide design and methodological support to health and social care researchers across England to develop grant applications to the NIHR and other national peer-reviewed funding programmes	Research related	National Research Design Service: http://www.rds.nihr.ac.uk/ Our local branch of the RDS: http://www.rds-sw.nihr.ac.uk/
Representative	-	A person chosen (or volunteering) to speak or act on behalf of others.	PPI term; research term	
Research	-	According to the Oxford Dictionary, research is "creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of humans, culture and society, and the use of this stock of knowledge to devise new applications". The important point there is that it has structure, rules and is driven by a need to know more – but to do so in a measured way.	Research term!	
Research governance	-	Refers to both the legal and ethical frameworks that ensure research is carried out to high standards and safely, as well as the process of implementing those standards. The Secretary of State for Health	Research related; clinical research	Research Governance Framework 2005: https://www.gov.uk/government/uploads/system/uploads/a

		publishes a revised Research Governance Framework for Research in Health and Social Care when laws that might affect research change – for example, the recent Mental Capacity Act 2005 meant changes to how people with some conditions should be cared for while involved in research.		ttachment_data/file/139565/dh_4122427.pdf The Health Research Authority has now taken over this role (of updating and implementing research governance): http://www.hra.nhs.uk/about-the-hra/our-plans-and-projects/replacing-research-governance-framework/
Research grant	-	Money awarded to a researcher to carry out the research in their research proposal. Usually a researcher will spend a lot of time refining their Research question and choosing their methods in order to write a research proposal to submit to a funding body (such as the NIHR). Often these organisations receive more applications for funding than they can award, so all applications are reviewed; sometimes researchers are sent away with feedback to improve their proposal and eventually a researcher may be successful in being awarded funding. The success rate can be as low as 20% (Medical Research Council 2015-2016).	Research related	
Research methods	-	The techniques used to carry out research. These can be Quantitative (dealing with numbers, quantities) or Qualitative (mostly	Research term; clinical research	A good basic book on Methods by Sage (publisher): https://uk.sagepub.com/en-

		dealing with words and experiences). In healthcare research, they can include surveys, focus groups, interview and workshops. Clinical research has different methods such as 'randomised clinical trials'.		gb/eur/research-methods-for-health-care-practice/book230915#contents
Research proposal	-	In order to persuade a funding body to contribute to a research project, a researcher or research team first has to build a proposal of the work they want to do. This can take a surprising amount of time and effort – experts in different areas and research techniques come together and decide on the actual question that the research will answer; they involve people who might be able to help them gather the data, they decide on how the data will be gathered and analysed to make sure it all clear and robust and they decide on what outcomes will 'prove' the answer to their question. They also need to show funders that they have involved the public and patients and have considered finances; that the researchers taking part are sufficiently qualified to do the work and so on. All of this, taken together, is a research proposal.	Research term	
Research Question	-	This is the precise outlining of what question a piece of research will answer, and defines the problem, what research has already been done, what this research will do and how and what the researchers hope to find out.	Research term	

Researcher	-	Someone who carries out research! Usually with a lot of training to understand the methods used in a particular 'discipline' of research, maybe followed by individual study (such as a PhD or Masters) and then a process of being supported by 'the academic community' around them to take on more work to gain experience.	Research term	
Residential care	-	Care for an individual, usually given to them within a 'home' rather than their own home or a hospital, and where they are able to access 24 hour healthcare and support. This may be 'rehabilitation' after an injury or illness or a longer-term solution for chronic conditions or those needing more intensive care and support.	Healthcare related	
SCN	Strategic Clinical Networks	In 2013 the NHS changed and NHS England was set up to run the 'NHS' side of healthcare. In order to make sure they work with all of the local partners, Strategic Clinical Networks were set up to bring together those who use, provide and commission the service to make improvements in outcomes for complex patient pathways using an integrated, whole system approach. The SCNs provide advice to clinicians about complex cases, try to make sure all healthcare meets standards and encourages innovation. They also have public and patient involvement in the form of the Citizen's	Organisation	More about the NHS Strategic Clinical Networks from NHS England: https://www.england.nhs.uk/ourwork/part-rel/scn/ The local SCN for the South West: http://www.swscn.org.uk/

		Senate or Assembly, formed of interested local people (much like a PenPIG for the NHS).		
Service user		A service user is anyone who uses or has used health and/or social care services usually due to a long-term condition or disability, but technically this can be anyone who has used a service.	Patient-related; Research-related	
Service-user led research		See ‘User-led research’ and ‘service user’ as well. This is research identified, led, directed or carried out by the people using a healthcare or social care service.	Patient-related; Research-related	
Social care	-	Some people need help and support to live at home or in the community. The sort of help they need is usually not medical, but includes getting dressed, help with shopping, reminders or help to take medication, help with bathing and personal hygiene. This all comes under the heading of ‘social care’, which is currently provided by local Councils or private organisations (not the NHS).	Healthcare related	
Statistics	‘Stats’	This is a branch of mathematics that collects, analyses and interprets numerical data and then attempts to see how ‘likely’ it is that an event occurred or will occur – for example, how likely is it that there is a link between drinking coffee and developing dementia? The word is used for the data collected (‘the stats’) as well as the methods and techniques used to analyse that data.	Research term	

Steering Group	-	Most research projects – especially those that have managed to secure funding – will be run by a group of experts, not just a single individual. This group will usually be formed of 'co-applicants' who helped to write a bid and secure funding; they may also invite other experts to be members of a group 'steering' the project to success. Being a PPI person on a steering group may take three or so years of regular meetings, but it does mean you are right at the heart of managing a research project.	Research term	http://www.invo.org.uk/what-is-a-steering-group/
STP	Sustainability and Transformation Plan	This new NHS England initiative is for the creation of LOCAL five year plans for "improving quality and developing new models of care; improving health and wellbeing; and improving efficiency of services. Leaders were asked to identify the key priorities needed for their local area to meet these challenges and deliver financial balance for the NHS. The plans needed to cover all aspects of NHS spending, as well as focusing on better integration with social care and other local authority services." They are generally created by the CCGs and local authorities responsible for an area coming together to create more 'integrated' healthcare that responds to the local population needs.	Organisation	https://www.kingsfund.org.uk/topics/integrated-care/sustainability-transformation-plans-explained

Systematic review	-	This is a well-planned, extensive and systematic review of all of the evidence that has been published on the effects of a particular medication, behavioural change, intervention etc. We often refer to a 'Cochrane review' – these are the world-leaders in producing systematic reviews. We also have a systematic review team in PenCLAHRC.	Research term	Cochrane: http://www.cochrane.org/ PenCLAHRC systematic review team: http://clahrc-peninsula.nihr.ac.uk/evidence-synthesis-team
Trial	-	When this is a 'clinical trial' then it is a study/project carried out in humans to discover or test the effects of an intervention (usually a medicine); to verify the safety of the intervention, what side-effects it may have, what unanticipated consequences and how effective it is.	Clinical research, research term	
Translational research	-	This is another term for 'applied research', often referred to as 'Bench-to-bedside research' that aims to take ideas tested in theory and make use of them quickly and efficiently. A lot of the work that the CLAHRCs do is in this area, trying to get good research and theory into practice as quickly as possible.	Research term	
User-led research	-	User led research (or 'Service-user led research') is usually seen as research which is led and shaped by service users but is not necessarily initiated, controlled or led by them. Control in user led research in this case will rest with some other group of non-	Research term	

		service users who also have an interest in the research, such as the commissioners of the research, the researchers or people who provide services.		

For further definitions, there are some very good glossaries online, and we will add to this as we go on.

- Clinical research
    - EUPATI glossary: https://www.eupati.eu/glossary/

- Healthcare research and public/patient involvement
    - INVOLVE Jargon Buster: http://www.invo.org.uk/resource-centre/jargon-buster/