



# Guide to research about childhood brain conditions

CEREBRA



Working wonders for children  
with brain conditions



# Working wonders for children with brain conditions

Families where a child has a brain condition face challenges every day. Just to learn, play, make friends and experience the world can feel difficult, even impossible. But we don't believe there's any challenge that can't be overcome.

So we listen to families, we learn from them. We carry out research, we design and innovate, we make and share. From new equipment to new learning resources, to new ways to play and support each other, everything we find out together makes life better. It opens doors to discovering the world.

It's an incredibly rewarding journey for everyone involved. Why not be a part of it? You never know what we'll discover together.

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Thank you.

# Guide to research about childhood brain conditions

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## Aims

This guide has been developed as an overview of research into childhood brain conditions for parents/ caregivers and lay people. It aims to provide you with the knowledge and resources to help you find and [evaluate](#) the quality of research and information you find about childhood brain conditions and associated subjects. Part one provides an introduction to research and the research process. Part two outlines suggestions and strategies for finding and ensuring you are reading good quality research and information. Part three provides a glossary of key terms (highlighted in [blue](#) throughout the text).

## Terms

Throughout the text we use the term 'brain condition'. By 'brain condition', we mean any neurodevelopmental disorder (NDD) that affects the developing brain, including those caused by illness, genetics or traumatic injury. Brain conditions include (but are not limited to) autism, ADHD, Down's syndrome, learning disabilities, cerebral palsy, epilepsy and developmental delay

## Key points

- Understanding childhood brain conditions
- Broad stages of the research process
- Understanding health research
- What helps to ensure good quality research?

# Part I : An introduction to research

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## Understanding childhood brain conditions

Research is the best chance we have of furthering our understanding of and improving life for children with brain conditions. Due to the varied and complex nature of the presentation, course and outcomes of different childhood brain conditions, professionals and organisations with the task of helping these children develop ideas and conduct research to better understand how to help and support them and their families.

A broad definition of research is that it is 'a *detailed study of a subject, especially in order to discover (new) information or reach a (new) understanding*' (Cambridge Dictionary). This detailed study can provide crucial information about a particular condition including cause, what the symptom range may be, methods of diagnosis, positive aspects and challenges associated with the condition and evidence in the development and establishment of treatments, therapies and management techniques.

Factual information based on research helps lay people and professionals make informed decisions.

## Examples of childhood brain condition research

There are numerous ways to think about research, for example by academic field, by method of [data](#) collection, by what the research study is about or what the [research question](#) is. In addition, research can often relate to more than one field. Some examples of research with a focus on childhood brain conditions include:

### Medical research

Medical research covers a wide range of fields, including differing specialties of medicine (fetal medicine, paediatric medicine, child psychiatry

etc) that focuses on better understanding childhood brain conditions, in order to develop new medicines and medical procedures, or improve the application of those already available. An example of medical research funded by Cerebra includes research undertaken at the University of Barcelona to identify brain injury biomarkers (or indicators) in perinatal life (the first weeks of life) to define measures for early intervention. Please [click here](#) to find out more about this research.

### Psychological research

Psychological research focuses on the study of the human mind and its functions, in particular human experiences and behaviour in given contexts. In childhood brain condition research, psychological research findings are essential to further our understanding of the behavioural presentation of different conditions and to inform policy, the design and evaluation of psychological interventions and to improve clinical practice. An example of psychological research funded by Cerebra includes research undertaken at the University of Birmingham, investigating emotional, cognitive and behavioural difference and disorder in individuals with intellectual disability, autism spectrum disorders and genetic syndromes. Please [click here](#) to find out more about this research. Useable information for parents, carers and professionals can be found on their [Further Inform Neurogenetic Disorders](#) website.

### Legal research

Legal research can be described as the process of identifying and retrieving information necessary to support legal decision-making. While quite different to health research, it is an important research area, with far reaching benefits for the child and family as a whole. Families of children with brain conditions are increasingly encountering problems accessing their legal

entitlements. An example of legal research supported by Cerebra includes the [Legal Entitlements and Problem-Solving Project](#) that aims to help families of disabled children overcome commonly occurring legal problems that they encounter when seeking to access their health, social care or other legal entitlements. The programme produces reports which are used to raise awareness and bring about practical change in the law, public policy and practices. (Please [click here](#) to find out more about this research).

## Broad stages of the research cycle

The following diagram shows the broad stages that researchers go through when designing and conducting health-based research about childhood brain conditions (point 1 through 10). By the time the research reaches the evaluation stage there are often many more questions generated, and the cycle continues.

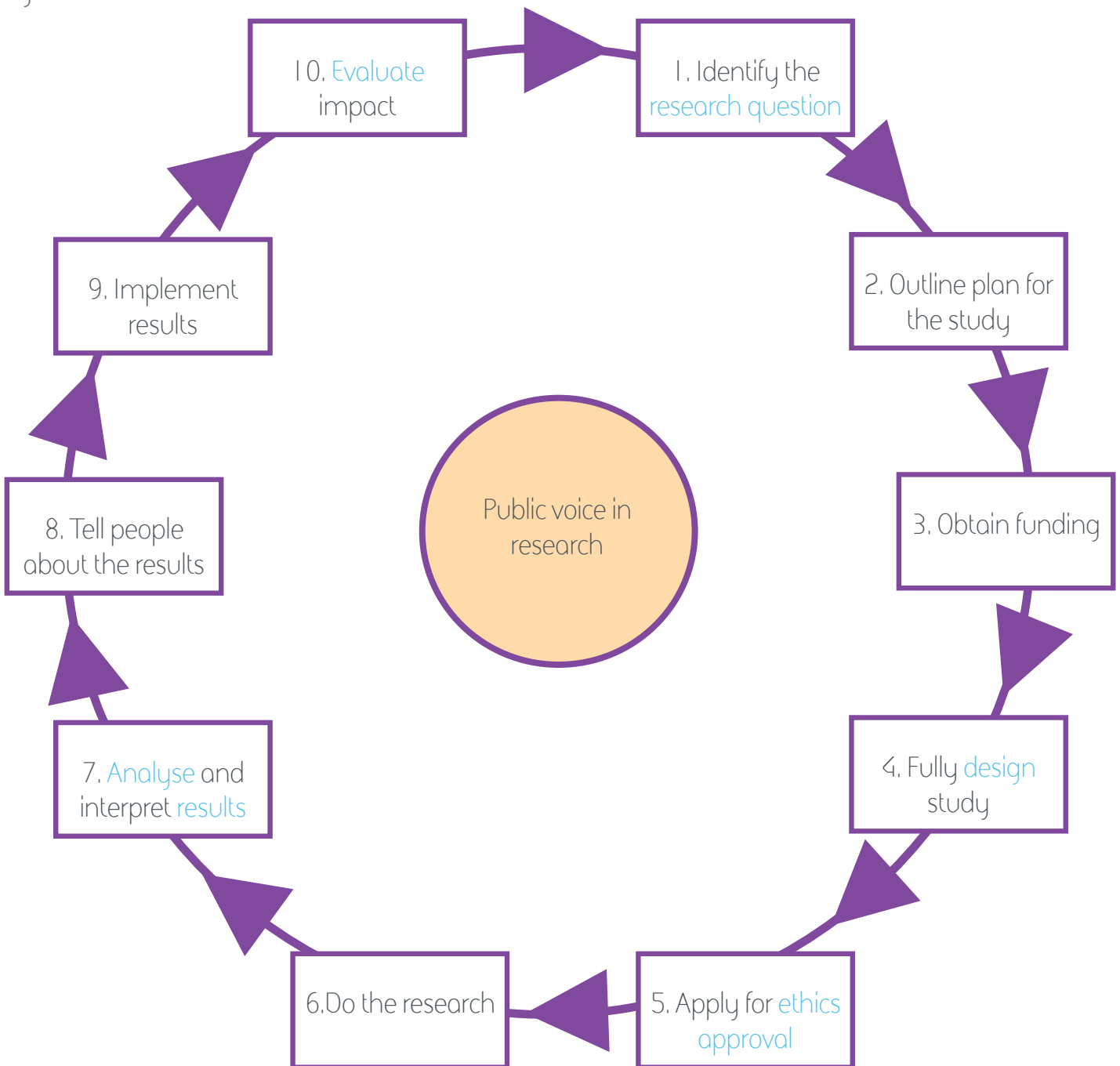


Figure 1: Adapted from NIHR (2017) The research cycle.

## Research design

Different research projects and different research fields use different research designs and methods depending on the [research question](#) the study is asking and the resources or funding available for the study. This introduction to research will focus on research relating to healthcare.

[Primary research](#) (or field research) is research in which new data is collected. [Secondary research](#) (or desk-based research) involves the use of data or research that has already been collected. [Primary research](#) can take a long time to conduct and is therefore expensive compared to [secondary research](#).

To read more about primary health research design and methods, please visit the [Centre for Evidence-Based Medicine](#) at the University of Oxford, whose webpage describes different study designs in medical research and a description of the advantages and disadvantages of each.

## Types of health research evidence

Figure 2 (opposite), shows the different types of research evidence (particularly in healthcare) in order of considered reliability (the most reliable at the top of the pyramid). The evidence further down the pyramid may need more assessment of quality (see Part 2 on page 10 of this guide for tips about how to assess research quality). For a full description of each evidence term, please click the title (in [blue](#)) to read more in the research terms glossary. The 'sources' section of the diagram suggests places to search for this type of research evidence (click the link to visit the site).

It must be noted that the research evidence hierarchy in Figure 2 is the traditional way of considering the usefulness and reliability of research evidence, particularly for [evidence-based decision-making](#), as research designs at the higher end of the hierarchy are less likely to be affected by bias and confounding factors (other factors that could be having an effect on the results).

To read more about levels and usefulness of research evidence, please visit the [Understanding Health Research website](#).



## Research Evidence Type

## Sources

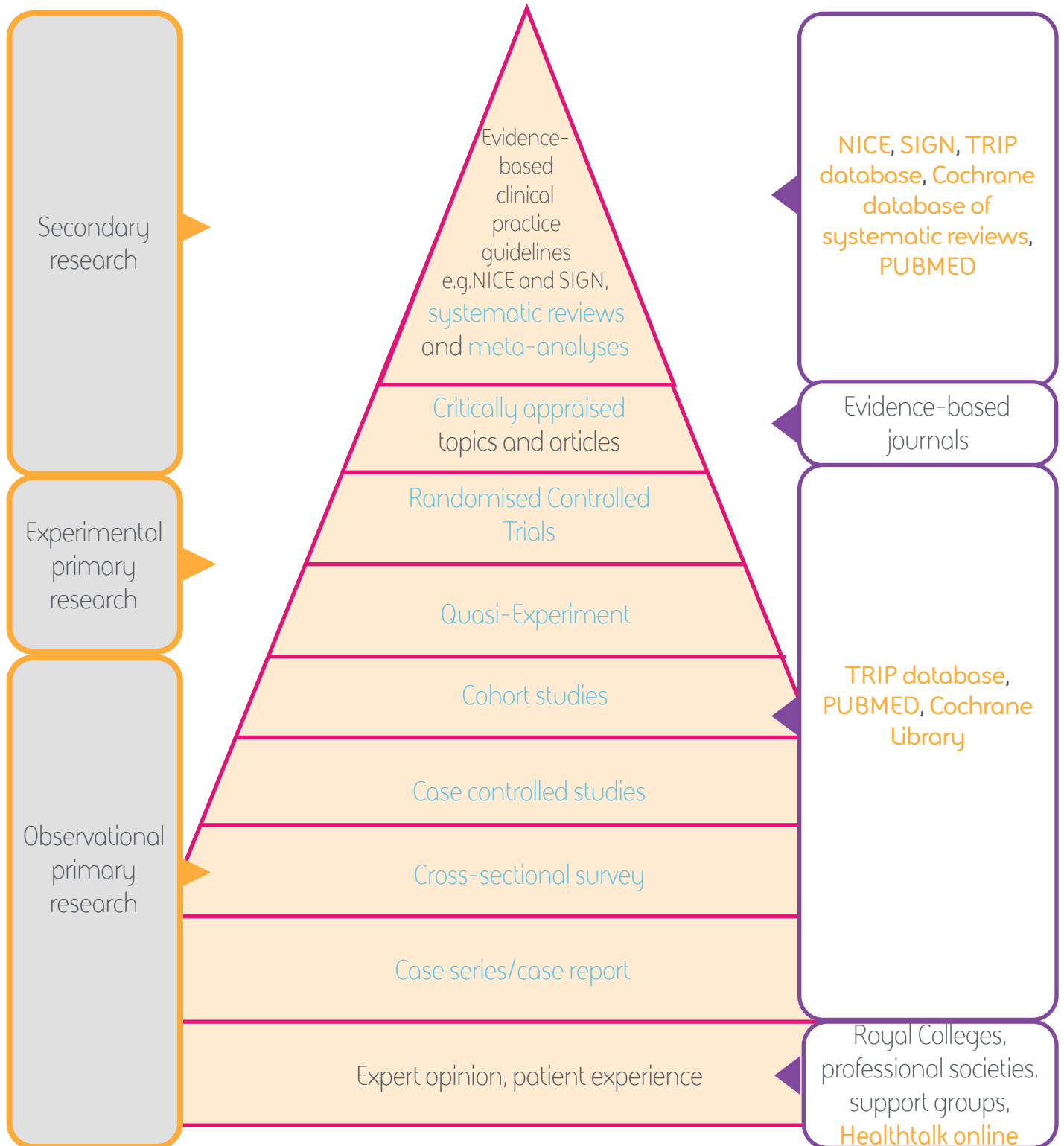


Figure 2: adapted from: DiCenso A, Bayley L, Haynes RB. (2009) Accessing pre-appraised evidence: fine-tuning the 5S model into a 6S model. *Evidence-Based Nursing*, 12(4), 99-101; and The Information Standard (2013) Finding the evidence. Information Standard Publication, available from <https://www.england.nhs.uk/wp-content/uploads/2017/02/tis-guide-finding-the-evidence-07nov.pdf>.

# Understanding Health Research

## How to read a scientific paper

This article from Understanding Health Research provides a useful introduction to the structure of scientific papers. Additional pages on the left hand side explain other useful information to help you understand health research.

<http://www.understandinghealthresearch.org/useful-information/are-some-types-of-evidence-better-than-others-22>

This open access article by Trisha Greenhalgh titled 'How to read a medical article' provides some useful information about getting your bearings when reading a medical article, [critically appraising](#) the research and provides a description of common [study designs](#).

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2127173/>

## What methods help to ensure researchers conduct good quality research and that findings can be relied upon?

### Research ethics

Research ethics govern the standards of conduct for scientific researchers to safeguard the dignity, rights and welfare of any human [participants](#) who have agreed to take part in a research study. It is a prerequisite that any research involving people must be reviewed by an ethics committee. Some questions committees might ask in establishing if the research is ethical and should proceed include:

- Is the research justified? Is it likely to add to the existing knowledge base?
- Is the research proposed of sufficient standard? Are the researchers qualified to conduct the roles proposed?
- Do the benefits of the research outweigh the risks to participants?

- Are there any conflicts of interest?
- Are plans for data protection adequate?

### Involving the public in research

The quality, relevance and integrity of research benefits massively from the involvement of the public in the research process. By definition INVOLVE outlines public involvement in research, as 'research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them'.<sup>1</sup>

'No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well'. Professor Dame Sally Davies, Chief Medical Officer.<sup>2</sup>

Members of the public can get involved in the research process at a number of stages. For example:

- working with those that fund research to prioritise research that really matters
- offering advice as members of a research project [steering group](#)
- helping to develop the [research question](#)
- commenting on and developing research design and materials
- applying for [research funding](#) and [ethical approval](#)
- helping to conduct the research
- telling people about the research. <sup>1</sup>

<sup>1</sup>INVOLVE (n.d.). What is public involvement in research? Retrieved from <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

<sup>2</sup>Staley, K. (2009). Exploring Impact: public involvement in NHS, public health and social care research. Retrieved from <http://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/>



Please visit the Healthtalk Online link below to find out about the experience of getting involved in the research process as a patient or member of the public.

<http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics>

### Peer review

Peer review is the system for evaluating the quality of research before and after it is funded or published. It involves having any research proposals, papers and publications reviewed critically by independent experts (peers). The review process is usually initiated by the funding body or the editors of a journal the work has been submitted to for publication.<sup>3</sup>

### Research replication

For research results to be taken as well-established, the finding needs to be replicated. Any important result will be subjected to replication by other researchers in the field. If the result cannot be replicated then the original findings are cast into doubt. This often leads to more research questions being devised to understand why the results could not be replicated, for example differences in research populations. To read more about research replicability please visit:

<http://www.understandinghealthresearch.org/useful-information/replicability-26>

### Research Excellence Framework

The Research Excellence Framework (REF) is the system for assessing the quality of research in higher education institutions. Results can be found on the REF website.

<https://www.ref.ac.uk/>



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<sup>3</sup>Research Information Network. (2010). Peer review – A guide for researchers. Retrieved from <http://www.rin.ac.uk/system/files/attachments/Peer-review-guide-screen.pdf>

# Part 2: Finding good quality research and information

## Key points

- What strategies are useful when searching for information and research evidence on the internet?
- How do I decide how trustworthy and useful my search results are?
- Where can I search for good quality health research and information?

There is an overwhelming and ever-growing number of sources of information and research evidence available in the public domain today, much of which is accessed via the internet. When searching for research evidence or information about childhood brain conditions on the internet, it is important to make a judgment about the quality of what you find before you use it. Anyone can publish information on the internet, so not all information can be relied upon to be trustworthy and up-to-date. This guide aims to provide some tips to help you search efficiently on the internet, find good quality research and information and provide you with some methods to check how useful the information is for your situation.

## What search strategies are useful when searching for information and research evidence?

Before you search for information it is important to plan your search strategy to maximise the useful results that you find.

### Structuring your question and defining your search terms

It is important to think about the question or topic you want to know more about, define your question and search terms (or key words) and write them down. Breaking down your question and identifying your concepts in this way will

improve the relevance and quantity of search results you find. Some things that you might want to consider when defining your question and key words include:

- The condition you are interested in (e.g. children with intellectual disability)
- The specific information you are interested in, for example, the symptoms of the condition, the effectiveness of a treatment or the prognosis etc.
- The outcomes you are interested in, for example, behavioural and emotional outcomes, or perhaps the effect of any treatment or therapy (e.g. treatment effect on anxiety)
- You might want to find evidence about how beneficial one type of treatment or therapy is compared with another.

Once you have identified your key words, you should then identify any synonyms (e.g. intellectual disability, learning disability etc).

Make a full list of these key words and synonyms to be used during your searches.

### Searching for research and information

In some websites you can use Boolean operators, or words to connect your search words together and define their relationship. This can narrow or broaden your search results. The most common Boolean operators are AND, OR and NOT.

- If you place AND between your key search words you will retrieve results that contain both words. (e.g. for children AND intellectual disability, you will only get results that contain both words). This narrows your search. If you don't use AND the search engine assumes an AND is between two words.
- If you place OR between your key search words, you will retrieve results that contain one word or the other, or both together. This broadens your search.
- If you place NOT before a search word, the search will exclude the results that contain that word. This narrows your search.

### Example

To retrieve information and research results about the query – ‘Does mindfulness therapy have an effect on aggressive behaviour in children with intellectual disabilities?’ you could search for Children AND (Intellectual Disability OR learning disability) AND Mindfulness AND aggressive behaviour.

## How do I decide how reliable and useful my search results are?

If you use general search engines (such as **Google** to find information or perhaps **Google Scholar** to find research articles), you will get a huge number of results that do not consider the quality of the information or research they find. This can be a good place to start your search but it is important that you use the information below to decide what information is trustworthy and up-to-date and whether it may be useful for your circumstances.

Some useful things to think about when deciding whether an information source can be trusted include:

1. Who is the author? What qualifications do they have in the area they are writing about? Be cautious if there is no author mentioned.
2. Does the information have a recorded date of publication and review date? It is important to make sure any information you use is up-to-date.
3. Is the information affiliated with a university, government agency, Royal College or other reputable organisation?
4. Does the information source provide references for the information used?
5. Has the information been reviewed by an independent expert?
6. Is there any evidence of bias? For example, information you find about a treatment or therapy may be biased as it may be written by the person who has developed it.
7. If the information is from a charity, do they have a registered charity number?

## Appraising Research

### Critically appraising research

Evaluating the quality and usefulness of the research to your situation is an essential task you need to complete before you rely on it. The following websites provide in-depth checklists so you can **critically appraise** and evaluate the usefulness of any research evidence you find.

The Critical Appraisal Skills Programme (CASP) provides an overview of some research study designs and checklists that are designed to help you critically appraise research, including things to consider when reading **systematic reviews**, **randomised controlled trials**, **cohort studies**, **case control studies**, **evaluations**, and **qualitative studies**.

<https://casp-uk.net/casp-tools-checklists/>

The Understanding Health Research tool aims to help you review a health research article by guiding you through a series of questions to ask of it (takes about 30 minutes). The tool provides

a summary of your answers to help you reach a conclusion about the research.

<https://www.understandinghealthresearch.org/>

## Where can I search for research?

Listed below are some useful places you can search for research evidence that only contain high quality research evidence unless stated.

### The Cochrane Library

The Cochrane Library is a collection of six databases that contain different types of high quality (including high quality systematic reviews) independent evidence to inform healthcare decision-making.

<https://www.cochranelibrary.com/>

### TRIP (Turning Research into Practice)

TRIP is a large search engine that enables users to search for high quality clinical research evidence fast.

<https://www.tripdatabase.com/>

### PubMed

PubMed comprises more than 28 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full text content from PubMed Central and publisher web sites. Many citations on PubMed will not have been appraised for quality and bias, so it is important to critically appraise the results found using the information provided in this guide.

<https://www.ncbi.nlm.nih.gov/pubmed/>

## Where can I search for health information?

### Cerebra

We aim to provide high quality health and social care information for the parents and carers of children aged 0-16 years with brain conditions.

<https://cerebra.org.uk/get-advice-support/>

### Contact

Contact provide medical information written by medical experts on a large range of childhood conditions, including information about symptoms, diagnosis and support.

<https://contact.org.uk/advice-and-support/health-medical-information/conditions/>

Contact provide lists of additional reputable sources of medical information in their 'Finding medical information' booklet.

<https://contact.org.uk/advice-and-support/health-medical-information/finding-medical-information/>

### Healthtalk

Healthtalk provides free reliable information about health issues by sharing peoples real life experiences.

<http://www.healthtalk.org/>

### NHS Choices

NHS Choices provide information about a huge range of medical conditions, including information about symptoms, causes, diagnosis and treatment of the condition.

<https://www.nhs.uk/Conditions/Pages/hub.aspx>

### Patient

Patient provides health information for patients and professionals around the world. The site contains over 4000 health information leaflets and thousands of discussion forums.

<https://patient.info/>

## Charities for individual conditions

There are numerous independent charities that offer support and information to individuals and families of children with brain conditions, for example Mencap for children with a learning disability and The National Autistic Society for children with autism. You can use the guidance above to decide how reliable their information is likely to be. Contact and NHS Choices provide links to associated organisations on their medical information pages.



# Part 3 - Research terms glossary

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## Abstract

In a research paper or article, the abstract can usually be found at the beginning and provides a summary, giving only the most important facts or ideas.

## Analysis

Analysis is the act of analysing something to examine in detail its elements or structure. Research analysis often involves data processing to answer the research question posed, using specialist computer software.

## Case study or Case series

A case study is a medical report of a single patient in the form of a story. A case series is a series of case reports that are compiled together to report on aspects of a particular condition. This type of study design can be useful to describe elements of the condition or treatment effects but is limited as it cannot compare with people who receive different treatment or those without the condition.

## Case control study

A case control study involves matching patients with a condition against a control group of patients (e.g. another group of individuals, for example, patients with another disease or healthy people) and making comparisons. Case control studies are usually conducted to find out what causes a condition, rather than treatment.

## Clinical research

Clinical research focuses on understanding human health and disease and finding ways to detect, diagnose, treat or prevent illness. Clinical research studies human participants, often with and without a particular disease. This may take the form of observing and examining individuals, x-ray scans or perhaps using samples of bodily tissues or bloods.

## Clinical trial

A type of clinical research that tests new treatments.

## Cohort

A group of people that share a characteristic. In research this can often be participant age.

## Cohort study

A cohort study is a form of longitudinal study design that follows a group of people (cohort) over a period of time. The cohort share a defining feature or characteristic.

## Conflict of interest

A conflict of interest may arise when a person is considered not to be able to make a fair decision because they will be affected by the result.

## Cross-sectional study

In a cross-sectional study, data is collected for the whole sample at one point in time to investigate the relationship between disease (or other health-related state) and other variables of interest.

## Critical appraisal

Critical appraisal is the process of carefully and systematically examining research to judge its trustworthiness (Burls, 2009).

## Data

Data is information that is collected when conducting research. It can take various forms including written facts or numbers. Data is usually inputted into a computer to be stored ready for analysis.

## Data Protection

The Data Protection Act 2018 applies to information about peoples 'personal data'. It sets out requirements for handling personal data by the government, businesses and organisations.

This must be carefully considered when conducting research. For more information please visit:

<https://www.gov.uk/data-protection>

## Descriptive research

Descriptive research is used to describe characteristics of a population or subject being studied.

## Epidemiology

Epidemiology is the scientific study and analysis of diseases. For example, epidemiologists may wish to find out how often a particular disease/condition occurs in different groups of people and why, how it is spread and controlled in different groups of people and in different conditions.

## Ethical approval

Ethical approval is an essential part of the research process that works to protect researchers and participants. Before research begins and researchers can collect data from participants, an ethics committee must approve the research plans. The committee considers things such as confidentiality and risk of harm before granting ethical approval.

## Evaluation

Evaluation is the critical appraisal or assessment of the value or worth or effectiveness of something. Evaluation might also measure progress towards goals.

## Evidence

Evidence can be defined as facts or information that exist indicating whether something is true or valid.

## Evidence-based decision-making

Evidence-based decision-making is a process by which decisions are informed by the best quality evidence available. The evidence used is focused on the questions of most importance for the decision being made.

## Evidence-based practice

Evidence-based practice means integrating clinical expertise with the best available evidence from research when making decisions about healthcare.

## Experimental research

Experimental research is a form of research in which one or more variable/s (thing/s of interest) is manipulated (changed) in order to see the effect on an outcome variable. When we conduct experimental research we can make statements about cause and effect.

## Feasibility study

A feasibility study is an initial investigation of how viable a research idea is, before going ahead with a full scale study.

## Focus group

A focus group is a form of qualitative research in which a group of people are brought together and asked about their thoughts and opinions about a particular subject, or perhaps to discuss potential solutions to a problem.

## Interdisciplinary research

Interdisciplinary research is a type of study that draws from more than one field of knowledge.

## Longitudinal study

A longitudinal study or survey is a research design that involves repeated observations of the same variables over time. Longitudinal studies allow researchers to study changes over time.

## Meta-analysis

Meta-analysis is a statistical approach that allows the integration of the results of several independent studies.

## Observational study

Observational research is a type of research in which the researcher observes naturally occurring behaviours. This type of research cannot look at what causes behaviours.

## Participant

A participant is a person that takes part in a research study.

## Peer review

Peer review involves subjecting an author's research or ideas to the scrutiny of other peers who are experts in the field, before the work is published.

## Pilot study

A pilot study is a small scale test of a study which aims to test the methods to be used in a larger scale study.

## Population

A population in research terms is all the people (or animals or anything else) that the researchers would like to find more information about. The population could be broad, for example, every person in a country or it could be narrow, for example, every male child under 16 with Down's syndrome.

## Primary research

Primary research involves generating new information (or data) yourself.

## Protocol

A research protocol is a detailed description of a set of activities for a proposed study and suggested timeline. A protocol should give a good description of what the proposed study is investigating and how the researchers propose to do it.

## Publication

A research publication distributes academic research.

## Qualitative research

Qualitative research is a type of research in which the methods used produce data that is not numerical.

## Quasi-experiment

A quasi-experimental design looks like an experimental design (such as a randomised controlled trial) but without the random assignment. These experiments are also used to look for causal relationships between an intervention and target outcome. However, due

to the lack of random assignment they are not considered to be as robust as an experimental design.

## Randomised controlled trial

A randomised controlled trial (RCT) is the gold standard clinical study in which participants are randomly allocated (by chance) to receive one of a number of clinical interventions. One intervention is the standard comparison or control group, meaning participants will receive standard practice, no intervention, or a placebo (e.g. a sugar pill). RCTs are the most effective method of finding out if an intervention has an effect on a particular outcome, but they are expensive to conduct.

## Research funding

The term research funding covers the financial resources provided for scientific research, most often in the form of money or sometimes effort or time. Research funding can come from a variety of places including non-commercial (charities, research councils, government departments, European Commission etc.) and commercial (industry and private companies) sources.

## Research methods

Research methods is a broad term but can be described as the way in which something is studied in order to discover new information. Methods might include methods of data collection (e.g. survey or interview) or methods of data analysis.

## Research proposal

A research proposal is a summary of proposed research, including a description of the issues or research questions that the research aims to investigate.

## Research question

A research question is an answerable query about a specific concern or subject. As part of the research process the researcher turns a research idea into a structured research question.



## Research results

The research results are the findings of the research study. The results section in a scientific paper outlines the research results (or findings).

## Sample

A research sample is a group of people, items or objects that are taken from a larger group (or population) to be measured, as the whole group would be too large to measure e.g. all humans.

## Scientific paper/article

A scientific paper/article is a written report of original research findings, written by the researchers that carried out the research. A scientific paper/article includes an introduction (to the topic), methods, results, discussion of findings and an abstract (or summary of the paper).

## Secondary research

Secondary research involves gathering existing data that has already been produced into one place.

## Stakeholder

Research stakeholders are people or organisations that have an interest in the research project or who affect or who are affected by its outcomes.

## Steering group

A steering group is a group or committee of experts that oversee a research project and ensure that the research protocol (detailed description of study methodology) is followed. The steering group also provide advice.

## Study design

The research study design is the overall strategy chosen to address the research question. It is the plan used for the collection of data, measurement of variables and the analysis of the data.

## Systematic review

A systematic review is a summary of the results of clinical healthcare research, particularly controlled trials, to synthesize the evidence for the effectiveness of healthcare interventions so an informed decision can be made about its use.

Systematic reviewers use a process called meta-analysis to pool numerical data about effects of the intervention. A systematic review is the highest quality source of evidence on healthcare interventions.



## About the author

Jane Margetson is the Lead Research Officer at Cerebra. She is currently undertaking research at the University of Warwick related to Cerebra's 1,000 families study. Jane has a background in psychology.

## About the reviewer

Dr Nicolas M. Orsi is a Clinical Lecturer and Specialist Registrar in Histopathology at the University of Leeds/Leeds Teaching Hospitals Trust. He holds a degree in Animal Science (University of Reading) and a PhD (University of York) focussing on the cellular stresses affecting mammalian oocytes and embryos during assisted reproduction. He subsequently moved to the University of Leeds where he undertook his MBChB (Medicine). His current research interests focus on gynaecological malignancies, infertility and obstetric disorders. He has also been and is involved with multiple small and medium-sized enterprises in the commercial development of academic research.

The findings of this report are those of the author, not necessarily those of Cerebra.

**First edition:** 2019

**This edition:** 2019

**Review date:** 2022



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