



**PenCRU & Family Faculty**

making childhood disability research  
more relevant, useful and accessible

# **PenCRU Family Faculty Handbook**



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# Welcome to PenCRU!

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The PenCRU team L to R: Fleur, Stuart, Chris, Bel, Annette and Alice

**Hello and welcome to the PenCRU and Family Faculty handbook. We want this handbook to be a clear statement about how PenCRU and the Family Faculty work together. This handbook was co-produced with members of our Family Faculty.**

## Here are some things parent carers in the Family Faculty told us:

*“To be able to come and make use of my intellect saves my sanity... people forget we had responsible jobs before we became carers”*

*“It’s as much about what I can learn from other members as what I can offer”*

*“An opportunity to meet other parents, who have now become my friends”*

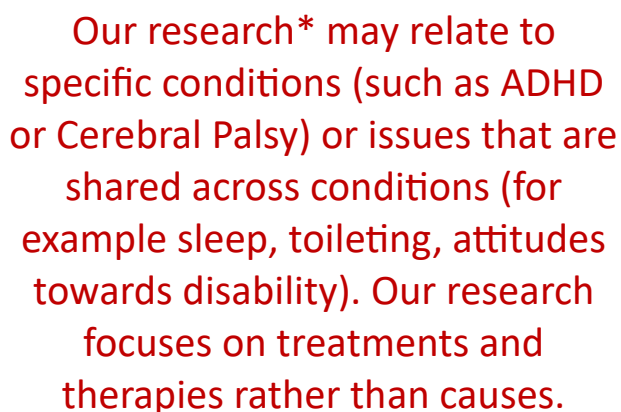
*“I feel valued equally without having to make the same level of commitment”*

# What is PenCRU?

PenCRU is the Peninsula Childhood Disability Research Unit based at the University of Exeter Medical School. The driving force behind PenCRU is our Family Faculty. Along with the Family Faculty, we seek to carry out research that aims to improve the health and wellbeing of disabled children and their families and that is useful and relevant to their lives.

## Who else do we work with?

We work in partnership with professionals from agencies providing health, social care and educational services for children across Devon. We also pursue research with colleagues engaged in childhood disability research across the UK and worldwide.



Our research\* may relate to specific conditions (such as ADHD or Cerebral Palsy) or issues that are shared across conditions (for example sleep, toileting, attitudes towards disability). Our research focuses on treatments and therapies rather than causes.

*We believe that a partnership between families, service providers and researchers is vital to improving the lives of disabled children and their families.*

## How are we funded?

The University of Exeter Medical School is currently funding our core team so we can:

- build partnerships with local families and service providers;
- identify issues and research questions and review the evidence of treatments and therapies, and then
- design research studies to address these questions.

For major research projects we need to apply for additional funding, for example to the National Institute of Health Research (NIHR) which is the government organisation that funds health related research in the UK. We have also benefitted from The National Lottery Community Fund for the delivery of the Healthy Parent Carers online programme.

## What does PenCRU do?

PenCRU carries out a broad programme of applied research that aims to improve the health and wellbeing of children with neurodisability\* and their families by utilising perspectives of families, researchers and professionals. Examples of conditions that neurodisability\* includes (but are not limited to) are Autistic Spectrum Disorder, Cerebral Palsy, Down's Syndrome, Attention Deficit Hyperactivity Disorder, Global Developmental Delay and Angelman Syndrome.

Fundamental to the ethos of the unit is the meaningful involvement of families affected by childhood disability in all aspects of our research and related activities. This includes setting our research agenda and deciding how to carry out specific research projects. We achieve this involvement through our Family Faculty.

## Definition of neurodisability

Neurodisability describes the group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour.

- Morris C, Janssens A, Tomlinson R, Williams J, Logan S. Towards a definition of neurodisability: a Delphi survey. *Dev Med Child Neurol*. 2013



# What work do we do?

## Respond to questions from Family Faculty members

We produce brief, easily readable summaries of the published evidence on topics or treatments that have been suggested by parents and carers. These are called 'What's the Evidence?'

## Develop and undertake research

We develop research questions that have been suggested to PenCRU by families or professionals. We also collaborate with other researchers on their ideas. Sometimes NIHR commission research on topics important to the NHS. Usually we need to apply for funding and if successful we carry out the research.



## PenCRU and the Family Faculty

## Communicate research

We raise awareness of what research is and produce 'plain language summaries' of research findings. We also communicate research through our website, social media and newsletters.

## Build partnerships

We build partnerships between families, researchers and health professionals. We have a learning programme called 'Building a Partnership' to support parents to be partners in research. Family Faculty members identify research related topics they would like to know more about and as a team we set up a workshop to investigate the subject together.

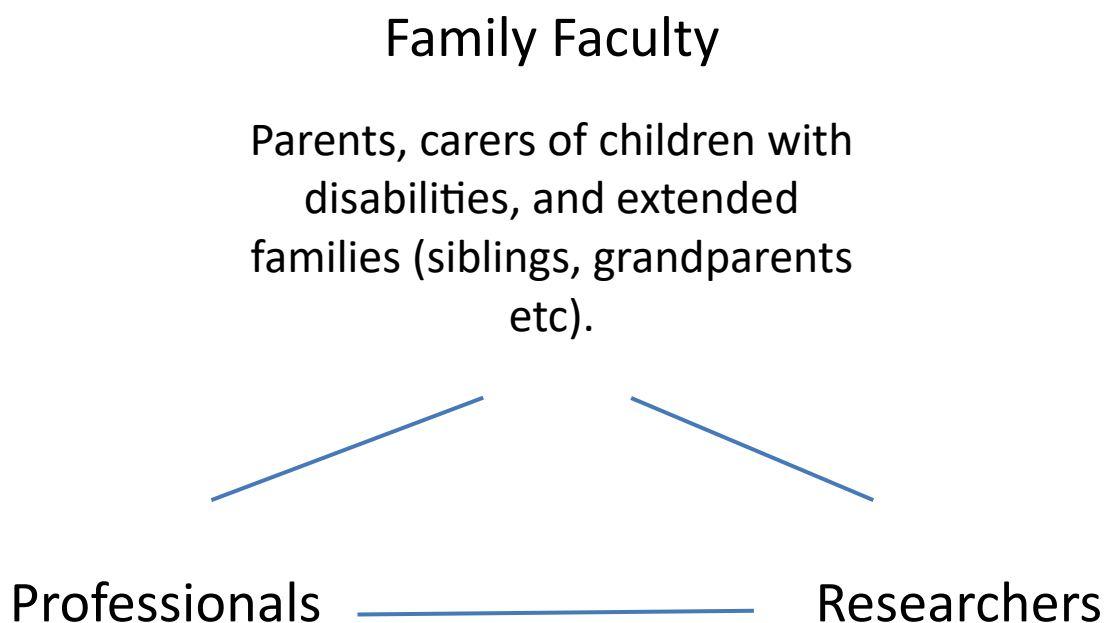
# What is the Family Faculty?

Our Family Faculty is made up of families and carers of children with neurodisability\*.

We take a 'life course approach' with Family Faculty members—although our research focuses on children and young people up to 25 yrs old, you can still join if your children are now adults!

Our ethos is to involve the Family Faculty in all aspects of our research and related activities. This includes setting our research agenda and deciding how to carry out specific research projects.

We would like families to work with us as part of the team; there is no need to have any experience of research. Getting involved with our programme of work is different to being a participant or a subject in research.





# Family Involvement in childhood disability research

## What is involvement?

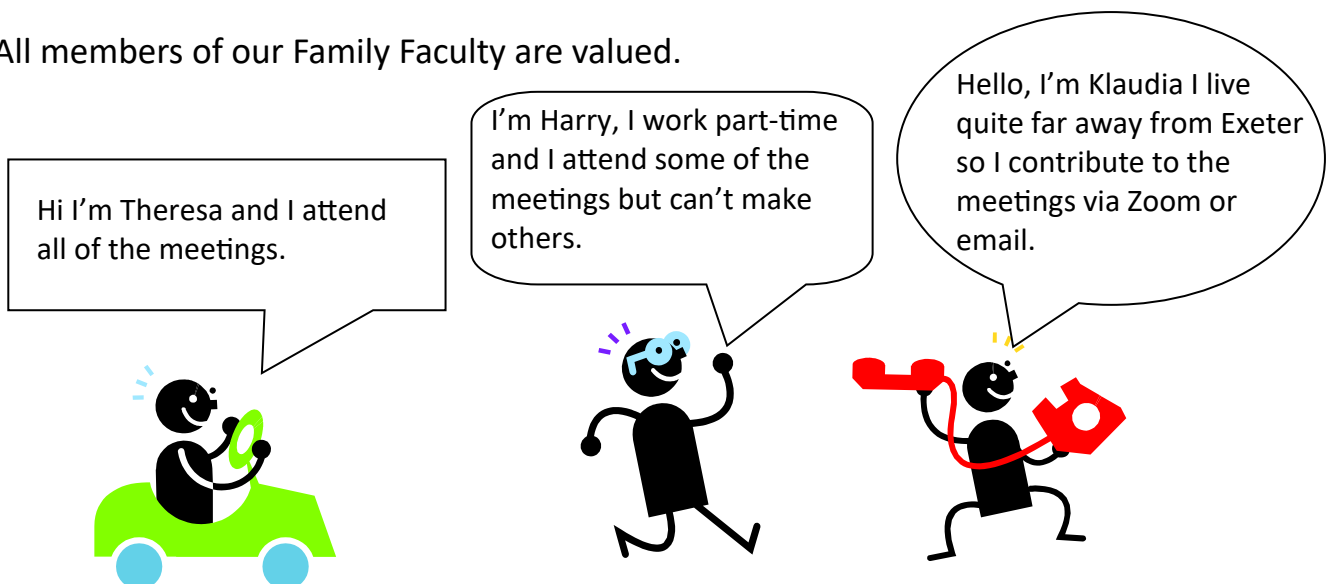
Involvement is giving families of disabled children a say in shaping our research programme. We support families to be part of the research team and be involved in many aspects of the research from what research we do, and how we design studies, to telling others about the results. Members of the Family Faculty can choose which activities to get involved with, and step in and out as it suits them depending on their circumstances at the time.

*We do research 'with' people, not just 'on', or 'to' or 'for them'.*

*- PenCRU ethos*

PenCRU have a mailing list for members of the Family Faculty. Through this, we keep everyone aware of involvement opportunities. We hold 3-5 meetings termly to discuss research projects. Families do not need to have any experience of research to attend these meetings. The expertise they bring is experience of being part of the family of a child with disability. Involvement in the project meetings can also be via Zoom or email.

All members of our Family Faculty are valued.



## Why involve families in research?

To ensure that the research PenCRU carries out addresses families and children's needs. We believe that by involving families we increase the effectiveness of research evidence in practice. Ultimately we hope our research will improve the health and wellbeing of disabled children and their families.



# How does PenCRU involve families in research?

Members of our Family Faculty are kept informed of different ways in which they can get involved. Examples include: suggesting research questions, being part of working groups, being co-applicants on funding applications and co-investigators on funded projects, being co-presenters at conferences and telling people about PenCRU and the results of PenCRU projects.



# Welcoming New Members

People interested in becoming a member of the Family Faculty can join in the following ways:

1. Enter contact information online on the PenCRU website.
2. Chat to a member of our team at an event/conference.
3. Contact PenCRU directly via email/phone.
4. Contact PenCRU via social media on our Facebook or Twitter account.

Once you have given us your contact details and a few optional details about your family, we will send you a welcome email. We will then keep you up to date with our current projects and opportunities for involvement. Expertise as a parent or carer is welcome at any meeting; experience of caring for a child with a condition specific to a project is usually not necessary.



If a member of the Family Faculty is interested in participating in a project group, they can do so by either attending the project group meeting or by contributing in other ways. We understand that some people can't attend meetings or prefer not to attend in person. If a person is unable to attend a meeting but would still like to contribute, we ask them to please let us know and we can arrange the best way for them to do that. Many of our Family Faculty members make valuable contributions in this way before and after meetings.

Due to Covid 19 all our meetings are currently held via Zoom. This has proved very beneficial for us, as parents who may struggle to attend meetings due to their caring commitments or who don't live locally are able to contribute more easily. When we are able to return to in person meetings, they will usually be held in the PenCRU offices in Exeter. We anticipate a blended approach to enable as many people to attend as possible.

## What you can expect from attending a meeting

Our PenCRU and Family Faculty meetings are friendly and informal. You will be treated as an equal and an expert. If you are attending a meeting held in Exeter you can claim back reasonable travel and childcare costs. We always include a lovely lunch in the meeting too! There is also an acknowledgement payment for your time when attending either online or in person meetings.

Please find details of our expenses and acknowledgement policies and forms in the [policy section](#) of the website.



## Buddy-up system for meetings

If you would like to attend a meeting we can put you in touch with another Family Faculty member who will also be attending the meeting. This will give you the opportunity to contact them prior to the meeting if you want to have a chat about what a typical meeting will be like. You will also be able to meet just prior to the meeting so you are not walking into an unfamiliar place on your own or entering a Zoom meeting where you don't know anybody!

If transport is an issue for you, we may be able to find a buddy who you can travel to the meetings with. The buddy-up system is of course entirely optional.

If you need support learning how to use Zoom we are very happy to help. We can set up a pre-meeting to help you feel more confident.

# Working Together

## PenCRU and Family Faculty 'Mutual agreement about working together'

It is important in all the workings of PenCRU and the Family Faculty that mutual respect and trust exists. To this end, all PenCRU staff and Family Faculty members are asked to read through and take account of the following list when working with PenCRU and other Family Faculty members.

### We agree to:

- \* Treat other Family Faculty members and PenCRU staff with respect and courtesy regardless of background. We are committed to equality, diversity and inclusion.
- \* Respect the confidentiality of information shared by individuals.
- \* Respect confidentiality concerning projects discussed. Please see the confidentiality policy for more information.
- \* Try and stay on topic during meetings.



Allow each other to speak in turn.

### Other things to remember!

- \* Nobody is 'just' anything, so no one is allowed to say 'I know I'm just a parent...'. Everyone's opinion is valued equally.
- \* There is no such thing as a silly question or comment.
- \* Please let PenCRU know if you can attend meetings, and also if circumstances change and you are no longer able to attend, so we can plan numbers for lunches and for parking permits.
- \* If there is any dispute with another Family Faculty member, or PenCRU member of staff, we ask people to please let us know. There is a formal procedure that can also be used if required. (Please see the complaints procedure policy for more information).



# What we use at meetings:



## Respect

We agree to treat Family Faculty members and PenCRU staff with respect and courtesy.



## Ask

There's no such thing as a silly question, so do ask if there's anything you're not sure about.



## Confidentiality

Respect confidentiality of information shared by individuals. Respect confidentiality concerning projects discussed.



## Allow each other time to speak

Take turns to speak and try to avoid talking when others are already speaking.

## Ground rules for PenCRU & Family Faculty meetings



## Nobody is 'just' anything

No one is allowed to say "I know I'm just a parent/ researcher..."

Everyone's opinion is valued equally.



## Remember the purpose of the meeting

Try and stay on topic during meetings, and remember the purpose of the meeting.



## Cameras

You may prefer not to use your camera but having it on helps with us interacting with each other.



## Confidentiality

There is the possibility that what is said might be overheard by other members of our households. Headsets can be used.



## Chat

You can use the chat function to tell us anything.



## Internet connection

If your internet connection is weak, turning off your camera may help.



## Microphones

It's best if we mute when we're not talking as background noises can be distracting for others.



## Background

You can blur or change your background if you don't want your room to be visible.

## Top tips for online meetings



## Talking

It's best to either put up your hand or use the raise your hand function if you'd like to talk, as Zoom struggles to cope if several people talk at once.



## Need to go..

If you need to disappear off-camera for a short time to deal with something at home, this is fine and will be understood by the group.



## Recording

Meetings may be recorded and screenshots taken, but we will always ask for your consent.

# The Research Cycle

Research projects go through a number of stages on the way to answering a question, shown in the research cycle diagram below. This cycle can sometimes be a long process. Click [here](#) for a list of words used in research and what they mean.



## Current Research Projects

There's more information about our current research projects and how you can be involved on the PenCRU website. [www.pencru.org](http://www.pencru.org)

# Involving Children and Young People

Our aim is to meaningfully involve children and young people in the activities of PenCRU in the same way we do with parents. We carry out research about children and their families and we would like to give children and young people a say in what topics we look at and how we carry out the research. We would like to know what children and young people think about our work and what things are important to them.



Working with children and young people with disabilities is complex and we have an evolving strategy to involve children and young people. We are building networks and contacts with schools, groups and organisations that we can call upon to develop our collaboration with children and young people. We are also liaising with experts from other organisations to gather as much information and expertise as we can to help us.



# Acronyms and phrases explained

**Advisory Group**— The Advisory Group usually meets twice a year to oversee the management of our unit; we discuss ideas and plans for our programme of work.

**Family Fun Day**—PenCRU's Family Fun Day is held each year to say 'Thank You' to members of the Family Faculty who have been involved in our work and research activities, and as a chance to get to know each other better! It's a free day out for families and takes place in a different location in Devon each year just after the Summer holidays.

**Information Leaflet**— Information leaflets are written to provide participants in a research study clear information about the study so they can make an informed decision about being involved. Our Family Faculty members can contribute to the writing and/or reviewing of participant information leaflets and help us think about how to inform participants about a study.

**NIHR**—National Institute for Health Research. The government funded research 'arm' of the NHS.

**Plain Language Summaries**—A plain language summary is a brief version of an academic paper or other document, that has been written to be accessible to everyone. It is written clearly, and includes explanations for any technical terms that are used. Our Plain Language summaries have been written by members of our Family Faculty and members of our research team together.

**Research**— We carry out research to find out more about a certain issue. This can involve discovering new information, adding to information that already exists, or questioning what is generally believed about something.

**Neurodisability**— Neurodisability describes the group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour.

**'What's the Evidence?' summaries**— Our 'What's the Evidence?' reports are an ongoing series of reports designed to summarise what is known about the effectiveness of a particular treatment or therapy. These reports are a synthesis of existing research and are not new studies that we have carried out. The reports are written in response to queries from families about the research that exists surrounding specific therapies and treatments. We produce reports about both NHS and complementary or alternative treatments.

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