



You Have a Voice In Research: Steps to Understanding

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There are Questions Burning in You

- “Why don’t they.....”
- “How come they haven’t found out.....”
- “I wish they would study.....”
- “What my child or family member needs is.....”
- “When are we going to find out.....”

Now Fill-In The Blank: _____

What is it that you want and need to know?

What about 3q29 Deletion Syndrome

- What is this health condition?
- How did I or my child get it?
- What does it mean for me and my family?
- What are the best treatments?
- Where do I (or my child, or family member) fit in among others who have 3q29 Deletion?
- What new knowledge is there to help us understand this?

Today's Objectives



To explain how health concerns are addressed by research



To explain research in understandable terms



To demonstrate and explain the different parts of the research process



To review who may be involved as planners, participants and users of research.



Addressing Health Concerns with Research



Everything Begins with a Research Question

What Do You Want to Know?

- Do children with anxiety who have Service Dogs have fewer seizure episodes compared to children without Service Dogs?
- What are the physical characteristics of people born with 3q29 Deletion Syndrome?
- How do developmental milestones of children with 3q29 compare with children of the same age who do not have 3q29 deletions?
- Do Social-Emotional Education strategies improve communication skills in children with 3q29 deletion syndrome compared to those who receive standard education?
- What is it like to live with 3q29 Deletion Syndrome?
- What is like to be a parent of a child who has 3q29 Deletion Syndrome?

Research Builds on Literature

What Do We Already Know?



**Existing Papers:
Literature**

**“Evidence-Based
Practice”**



How to look for it?

Asking a “PICO” Question

P = Patient or Population

I = Intervention

C = Comparison

O = Outcome

The Research Question Leads to Objectives or “Aims”

What is the Study About?

- Objectives are the key areas that a study will focus upon to answer the Research Question
- The objective will set up the Hypothesis: What do we think will happen?

Objective: To compare quality of life in parents who attend support groups with who do not

Hypothesis: Parents of children with 3q29 deletion syndrome who maintain consistent support group contact over 6 months report better quality of life compared to parents who do not maintain contact.



Aims Lead to Methods

How Will the Study Be Done?



Who are we studying?



What is the intervention
("Treatment")



How will the intervention
be delivered ("Protocol")



What data is being collected and how?



How will the data be
analyzed?



What steps have
been taken to avoid
bias?



Bias affects results
when there is undue
influence that
affects the findings
one way or another

Methods Tell Us About the Quality of Research

Is the Study Good Enough to Trust?

- The sample needs to be appropriate for the research question
- If it is comparison study there needs to be enough people in each comparison group.
 - The groups have to be similar except for the Intervention (treatment arm)
 - The Intervention must be delivered the same way for each person in the treatment group
- Bias must be anticipated and managed
- Analysis plans must anticipate if any data is missing, or if people drop out of the study



Methods Leads to Data Collection

What Kind of Information is Being Collected?

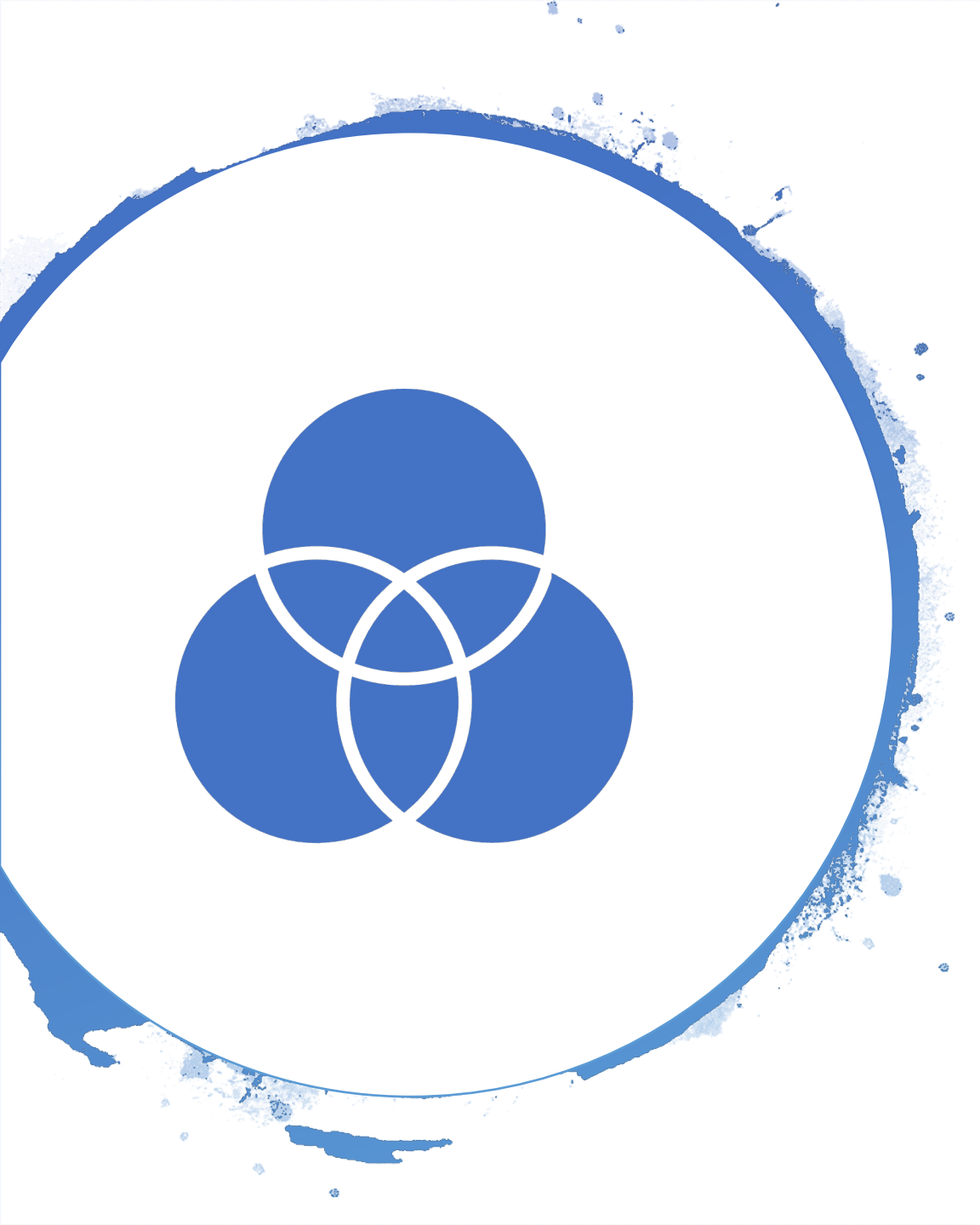
- What are we measuring?
 - Physical measurements: Height, Weight, Eyes, Ears,
 - Psychosocial measurements: Mood, Depression, Anxiety, Quality of Life
 - Imaging measurements: Density of brain matter
- Are we measuring according to well-known standards?
- Are we collecting data the same way each time?


Data Collection Leads to Analysis

What Are the Statistical Relationships

- If the study made a comparison, are there differences that are true?
- Are there relationships between or among things that are true?
- Are the results accurate and can you trust the findings?

If Methods are not good, and the study was not done well, statistics may not be accurate and the findings may be incorrect.





Analysis Leads to Results *What Did We Find?*

- **Difference** between groups
 - Did Group 1 fare better than group 2?
- **Relationships** between or among things
 - Was there a positive or negative relationship between things?

For example:

Kids who report fewer friends have
higher risk for depression

Or

Parents who take support training
classes show lower risk for depression

Every Study Has Limitations

Given that no study is perfect, what must we consider before trusting the results?

- Researchers should acknowledge:
- Not having enough people in the study
- Too many people dropped out
- How they handled missing data
- What measures they took to be sure that their conclusions were accurate



Study Results Lead to Discussion

How Do These Results Fit In With What is Known?

Researchers report their findings and compare them with what is known.


They discuss why their results might agree or disagree with the findings of others.

They synthesize their work with others and make recommendations about the use of their findings and recommendations about new research in the future

- What are the final results?
- How do these results filter down to patients and families?
- How much and kind of results are useable by patients and health care providers.
- Can results of this study be combined with other studies to make a change in the way the condition is managed?

Conclusions and Implications

Can These Results Be Used in Real Life?



YOU Can Be a Part of the Research Process

Patients and families have questions and concerns that they need answers for.

Some these can and must be investigated through research.

Patients and families need to tell clinicians and scientists what research would be meaningful them.

Without research new treatments or new understanding of medical conditions cannot be offered.

Becoming a Research Participant

- Be sure that the institution or organization has institution approval that protects your safety and privacy
- You or your child will be screened to see if you are right for the study
- The researchers will explain the study to you and ask if you would like to participate.
- You will be asked to sign an Informed Consent (Parents of children less than 18 years of age must sign a consent for their child and if the child is over 6 years of age, they must sign an Assent indicating their willingness to volunteer.
- Informed consent can be revoked at any time.
- You always have the power of decision not to participate in any part of the study, if you wish

Who Are Research Stakeholders?

It Takes a Village

Patients

Families

Clinicians

Scientists

Medical
Institutions

Policy
Makers

Insurance
Providers

Public

***“If you want to go fast, go alone,
if you want to go far, go together”***

An African Proverb



SANDBOX EXERCISE

GO TO ASSIGNED BREAKOUT ROOM

CREATE/DESIGN/THINK-UP

WHAT DO YOU WANT TO BE STUDIED?



Name 2 Things You Would Like Answers For

- 1.

- 2.



Which One is Most
Important to the Group?

Let's Build a Research Project !

- Using Your Ideas About Things That Matter to You.....
 - Create a Research Question

