CFReSHC

Cystic Fibrosis Reproductive and Sexual Health Collaborative

RESEARCH 101

CFReSHC Eugene Washington Award Team



3. Outline processes of disseminating scholarly activities associated with research

Overview of the Research Process



What is the purpose of research?

- To systematically answer a *question*
- Questions state what you want to learn
- What kinds of *questions*?
 - About the relationship between two things
 - Example: Can regular exercise replace 1 or more treatments daily?
 - Exploratory questions
 - Example: why are some patients more adherent with their treatments than other patients?



A Research Question

- 1. Expresses curiosity about the 1 or more phenomena
- 2. Also describes a population under study

Example:

Do adult patients with CF have better health outcomes if they are seen at their CF clinic every quarter or once a year?

- 1. Frequency of CF clinic visits (quarterly vs. annually)
- 2. Health outcomes
- 3. Population: adults with cystic fibrosis

Nature of a Good Research Question

- F.I.N.E.R
 - <u>F</u>easible
 - Interesting
 - o <u>N</u>ovel
 - <u>E</u>thical
 - <u>R</u>elevant



Types of Research

Quantitative:

- Numbers
- Statistics
- "How much"

<u>Qualitative</u>:

- Narratives
- Experiences
- "How"/"Why"



Mixed Methods:

- Combine both



Study	Quantitative	Qualitative
What is measured?	Numbers	Stories
Questions asked	Where, when, how much, how many?	What is happening, why?
Scope	Broad	Deep
Generalizability	Can be generalized to others besides study participants	Information only about people studied

Adapted from: Ofanoa M, Goodyear-Smith F. 2018. How to do Pacific research: a beginners guide. University of Auckland.

Study	Quantitative	Qualitative
Data	Numbers	Text
Participant Selection	Random or all	Selective
Participation Numbers	Many	Few
Participation Setting	Experimental	Natural
Analysis	Count, add, etc	Read, interpret

Adapted from: Ofanoa M, Goodyear-Smith F. 2018. How to do Pacific research: a beginners guide. University of Auckland.

Design Features

- Retrospective vs.
- Prospective
- Observational vs.
- Intervention



Retrospective vs. Prospective

- Retrospective
 - Use existing records or information
 - Look back in time

- Prospective
 - Generate new information
 - Follow research subjects forward





Retrospective vs. Prospective: CF Example



Observation vs. Intervention

Observational Design

- The investigator *does not* alter events or situations under study
- Study can be prospective or retrospective

Intervention Design

- Researcher *intentionally alters* study environment or situation
- Prospective

Anatomy of a Grant Application

Anatomy of a Grant



Grant Process Overview



Your project is complete, now what?

Sharing Your Research (Dissemination)

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TART	EXAMPLE	
 dentify outlet Conference presentation Scientific publication Newsletter Article Blog post 	Conference presentation Abstracts include:	
	Conference accepts or rejects abstract	 Conference presentation Oral Poster



Sharing Your Research (Dissemination)

Newsletters:



CFRI's 31st National Cystic Fibrosis Family Education Conference: **Speaker Abstracts**

At CFRI's 31st National CF Family Education Conference, Bridges to the Future, held August 3 to 5, 2018, nationally-renowned speakers from across the country shared their expertise and experience on a wide range of CF-related topics. Nine of these presentations were recorded and are available for viewing on CFRI's YouTube channel. The abstracts below provide a brief overview of each talk, followed by a link to the specific presentation.

CF Pipeline: The Journey Continues Manu Jain, MD-

Northwestern University School of Medicine

Life expectancy in cystic fibrosis (CF) has improved substantially over the last 75 years, with a median predicted survival of approximately 47 years. This has been due for the most part to therapies that have targeted lung disease and other end organ manifestations in an attempt to disrupt the cycle of mucous obstruction, inflammation, and infection. In an effort to develop drugs in the CF transmembrane conductance



regulator (CFTR), the Cystic Fibrosis Found- Over the past decade the focus of emerging ation embarked on a bold initiative in which therapies has shifted toward discovering it established collaborations with biopharma- drugs that target the underlying genetic that would target the underlying defects ceutical companies to support early-stage protein defects in CF, collectively referred efforts to discover new medicines for CF.



Localization of Secretory Mucins MUC5AC and MUC5B in Normal Human Airways Kenichi Okuda, MD — University of North Carolina

Rationale: Mucin secretion is one of the key Objectives: To characterize the regional discomponents of the mucociliary clearance tribution of MUCSAC and MUCSB in normal (MCC). Dysregulated mucin secretion can human airways and assess which cell types produce MCC dysfunction and worsening produce these mucins, referenced to club of chronic lung disease including cystic cell secretory protein (CCSP).

Social Media:



Today, the U.S. Food and Drug Administration approved ivacaftor (Kalydeco) for babies as young as 6 months who have one of 38 CF mutations.

The growing body of data on early treatment continues to support our belief that starting on modulators at a young age has the potential to help slow or even prevent progression of the disease. Ivacaftor was first approved in 2012 for people ages 6 and older with one specific CF mutation.



http://cfri.org/ https://www.cff.org/ http://cfreshc.org/

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Additional Terminology Resource



Research 101 Glossary: https://reachnet.org/wp-content/uploads/2017/04/Research-101-Glossary.pdf

