UNC | LINEBERGER COMPREHENSIVE CANCER CENTER

UNC CANCER CARE

Advocacy in Action:

Giving Feedback That Shapes Better Cancer Research

how to give meaningful feedback on ….

Learning Together

ASPIRE

Advocates & Scientists Partner in Research Education

Patty Spears, BS FASCO

Lineberger Comprehensive Cancer Center

LEAP

Lineberger Excellence in Advocacy Program

February 27, 2026

Tasks and Tools

Clinical Trials

- Reviewing trials for importance to patients — **concepts and protocols** ✓
- Helping patients understand trials — **public & patient materials** ✓
- Preparing patients for a trial — **consent forms**

Research Projects

- Reviewing a good summary — **lay/public abstract** ✓
- Lending your support to a new project — **letter of support** ✓
- Helping identifying how this research will help patients — **impact statement** ✓
- Telling funders who you are — **biosketch**
- Reviewing grants for funding — **grants**

Clinical Trials

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Idea for a trial

Developed in committee or study team

Concept is written

Review
Refinement

Protocol is written

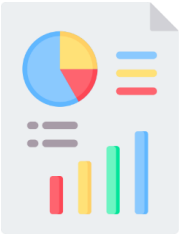
Trial is opened

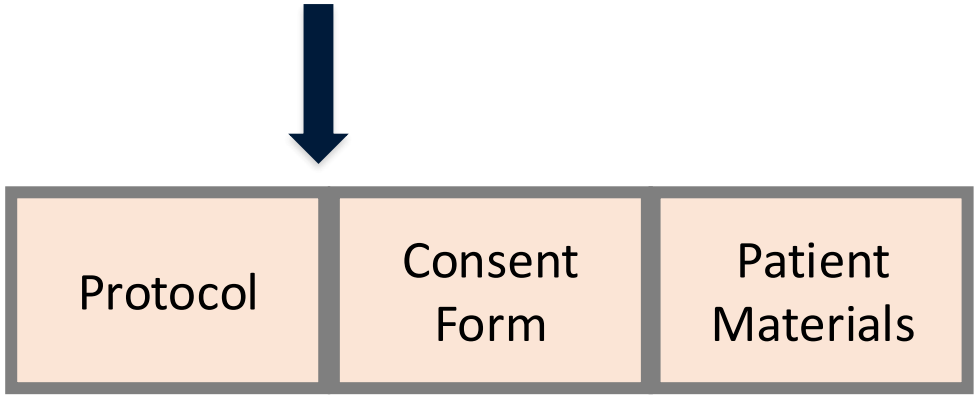
TRIAL
IS OPEN

DSMB Review

Trial is Done!

Results are published





UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Concepts and Protocols

Purpose

Concept

- First step in developing a clinical trial
- High level

Protocol

- A detailed plan of a scientific or medical experiment, treatment, or procedure

Content

Concept

- What question is being asked
- Scientific rationale
- Trial design, statistics, feasibility

Protocol

- Everything to run the trial
- what the study will do, how it will be done, and why it is being done

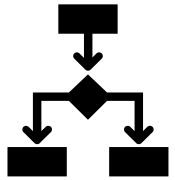
Clinical Trial Timeline - Concept to Protocol

Concept

~10 pages

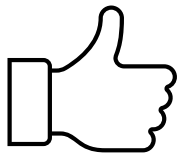
Protocol

~150 pages

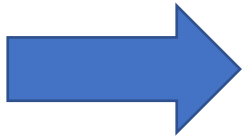


design

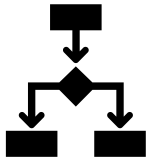
eligibility



feasibility



Expanded from the concept with more detail



design

eligibility

feasibility

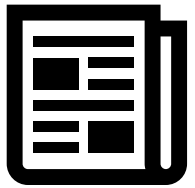
In the protocol, NOT in the concept (selected)

your choice

consent form

PROs

corr. studies



patient materials

What do advocates bring to the discussion?

Assure **relevance of the research questions** to patients and community

Evaluate other practical issues such as **accrual, feasibility**, etc.

Provide input on the **design of the clinical trial**

When reviewing a clinical trial:

Represent the **perspective of the patient community**, not your personal perspective

Have a basic understanding of the **research process**

Have a basic understanding of the **disease being studied**, including standard of care

Connect with **patient communities**

Understand the **responsibilities** at various points in the process

What do you look for? Guidance Documents Help!

The Alliance for Clinical Trials in Oncology (concept review)

- Study Impact
- Study Feasibility
- Level of Innovation
- NCTN Relevance
- Study Design
- Overall Impression

National Cancer Institute Steering Committee (concept review)

- How important is this trial to people who have been or will be diagnosed with this disease?
- What aspects of this trial design might attract patients or be of concern to patients?
- How well does this trial balance the risk, benefits, and burdens of the patient and/or the caregiver?
- What effect will the eligibility/inclusion and exclusion criteria have on the target patient population?
- Is this study likely to be able to meet accrual goals and retain patients through completion of the protocol?
- Are there other patient-related issues that should be considered at the Concept Evaluation Meeting?

Protocol Review at UNC – Advocate Review Form

Questions	Comments/Concerns
STUDY IMPACT TO PATIENTS	
What aspects of this trial design might attract patients or be of concern to patients? 1. Likely to lead to longer progression free survival? 2. Is the drug or intervention easy to take? 3. Are expected side effects and Quality of life burden comparable to standard of care? 4. Are the expected side effects LESS than Standard of Care? 5. Is there a Quality of Life component where patients can give feedback? 6. Is crossover allowed where appropriate	
Eligibility questions 1. Are the eligibility criteria noted in the protocol too unnecessarily strict and thereby reducing or eliminating potentially more diverse populations?	
Time demand questions 1. Are the time demands, number of visits, procedures, and interventions as stated in the protocol reasonable? 2. How does the study protocol compare to standard of care in terms of extra visits or procedures? 3. Are there procedures which appear problematic or unreasonable? Why?	
Justification questions? 1. Will the innovation really matter to patients, or is it just 'interesting science'?	

What does the advocate consider?

- Look at eligibility criteria
  - Inclusion – who can get on the trial
  - Exclusion – who can not get on the trial
- Review questionnaires that are also called Patient Reported Outcomes (PROs) Measures
- Review schedule for patient burden
- Review the consent form and help write parts if they are struggling to keep it at a good readability level
- Review patient materials if available

What do advocates consider?

Is the trial complicated? Do we need patient ED materials?

Are there added costs to patients?

Will results still be relevant when completed?

Is crossover allowed?

Are the patient exclusion and inclusion criteria appropriate?

Will PROs be included in the trial?

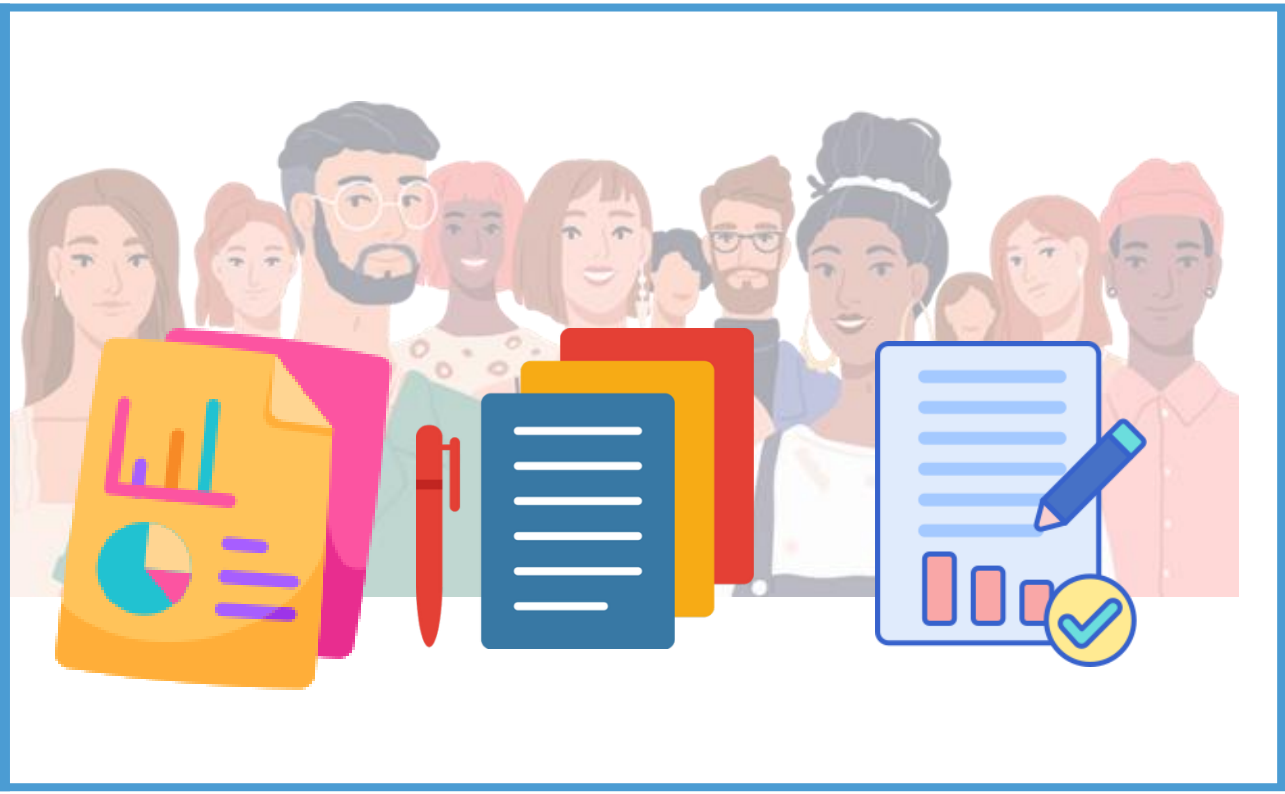
Is there randomization? Is it acceptable by patients?

Is the accrual target realistic?

Will this make a difference in patient care? In a positive way?

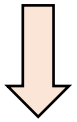
Will participation be hard for patients?

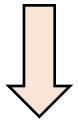
Public & Patient Materials (communication)



UNC | LINEBERGER COMPREHENSIVE CANCER CENTER

Draft Written	Content Expert Review	Health Literacy Consultant Review	Patient/Community Advocate Review	Final Version IRB approved
By PART or Study Team	Review for accuracy	Review for understandability and readability	Review for understandability and clarity	Study Team Finalizes





Advocates help draft documents

- Lived experience
- Language for the public

Advocates review documents

- Understandable
- Actionable

Updating the materials review form

- **PEMAT** - Patient Education Materials Assessment Tool

  An Instrument To Assess the Understandability and Actionability of Print and Audiovisual Patient Education Materials

  "The Patient Education Materials Assessment Tool (PEMAT) is a systematic method to evaluate and compare the understandability and actionability of patient education materials. It is designed as a guide to help determine whether patients will be able to understand and act on information. Separate tools are available for use with print and audiovisual materials."

- Link to site

UNDERSTANDABILITY

Item #	Item	Response Options	Rating
Topic: **Content**			
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	
Topic: **Word Choice & Style**			
3	The material uses common, everyday language.	Disagree=0, Agree=1	
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	
5	The material uses the active voice.	Disagree=0, Agree=1	
Topic: **Use of Numbers**			
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	
Topic: **Organization**			
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short material*=N/A	
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material*=N/A	
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	
11	The material provides a summary.	Disagree=0, Agree=1, Very short material*=N/A	
Topic: **Layout & Design**			
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1 Video=N/A	

Item #	Item	Response Options	Rating
Topic: **Use of Visual Aids**			
15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	
16	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	
17	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	

Total Points: _____

Total Possible Points: _____

Understandability Score (%): _____

(*Total Points* / *Total Possible Points*) × 100

ACTIONABILITY

Item #	Item	Response Options	Rating
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=NA	
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	
26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	

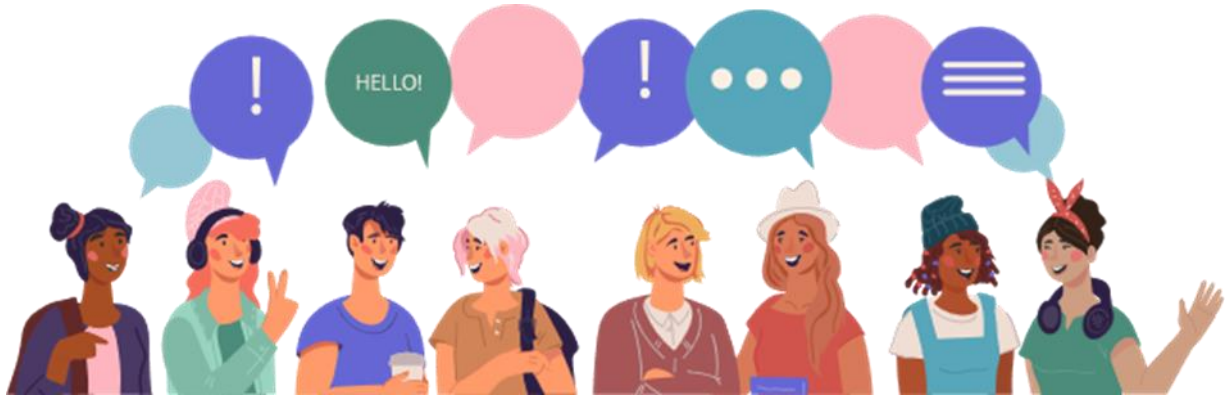
Total Points: _____

Total Possible Points: _____

Actionability Score (%): _____

(*Total Points* / *Total Possible Points*) × 100

Examples: Advocate Feedback in Action



Development of a General Information Sheet

ctDNA

It began as 2 pages (Feb 2025)

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Could a blood test help us detect cancer?

Learn more about using **ctDNA blood tests** for cancer

Why are circulating tumor DNA (ctDNA) blood tests important in cancer research?

- Researchers want to learn more about how to use this test to manage breast cancer treatments better.
- Researchers are looking at different ways to use ctDNA blood tests:
  - Diagnose cancer
  - Monitor how drugs are working during and after treatment
  - Determine whether more or less treatment is needed
- Being able to look at ctDNA in a blood sample is easier for you than doing a biopsy and your doctor may be able to see cancer sooner than with a scan.
- Similar to how we use a blood test to detect presence of cholesterol or blood sugar, we may be able to use a blood test to detect cancer.

Special Note

- Many ctDNA tests are being used in clinical trials to learn how to use the test to guide treatment of patients.
- Some ctDNA tests are Investigational which means it may not be approved for the condition being studied.

What is DNA (deoxyribonucleic acid)?

- Cells in your body contain genetic information called DNA.
- DNA from tumor cells and from non-cancerous cells can be released into a person's blood.

There is still a lot we need to learn about ctDNA!
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.

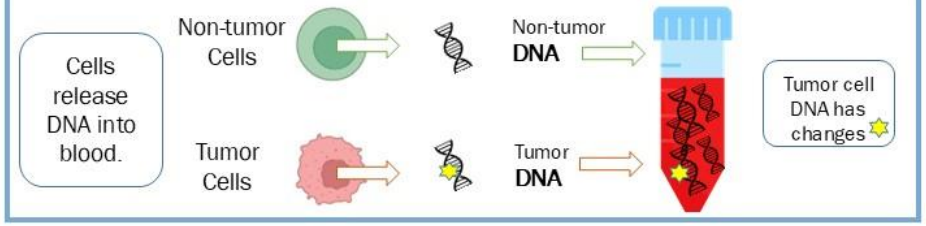
You can help us by taking part in a cancer research study!

Find a clinical trial at UNC Chapel Hill QR R4M

What is ctDNA (circulating tumor DNA)?

- Small pieces of DNA released into a person's blood from tumor cells are called ctDNA.
- DNA can include **changes**, called mutations.
  - In tumor cells, DNA contains mutations that are specific for the tumor cells.
  - These changes are not found in non-tumor cells.

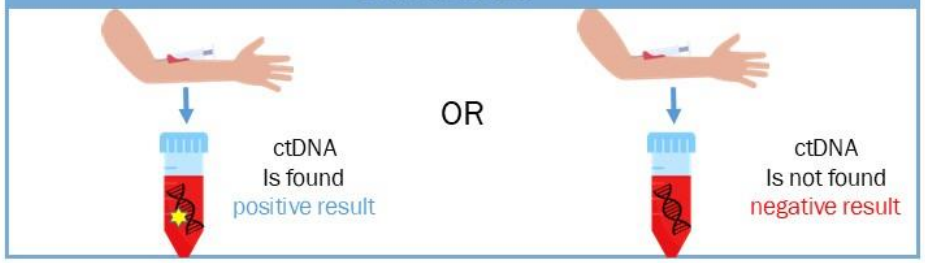
ctDNA in a blood sample



How can ctDNA be measured?

- There are special blood tests to look for and measure the amount of ctDNA in a blood sample.
- A blood sample is taken from a person to test for tumor DNA.
- The test can find the tumor DNA by looking for the changes that make it different from non-tumor DNA.
- There is usually only a very small amount of ctDNA in each blood sample.

ctDNA blood test



What are the possible results of the test?

There are two possible results on the test:

- ctDNA **is found** in the blood sample: This is a positive result.
- ctDNA **is not found** in the blood sample: This is a negative result.

Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.

COMPREHENSIVE
TER

Jordan said she could do this in one page!

And she did (Feb 2025)

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Could a blood test help us detect cancer?

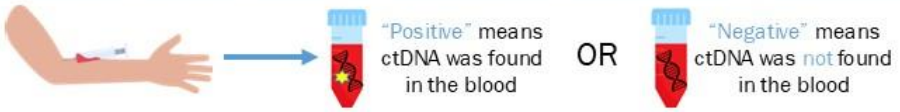
Similar to how we use a blood test to detect presence of cholesterol or blood sugar, we may be able to use a blood test to detect cancer.
Much easier than a scan or a biopsy! ☺

A blood sample can contain healthy cells and tumor cells.
Both healthy cells and tumor cells have DNA – a genetic recipe.
However, tumor cell DNA has specific changes called mutations (✸). Healthy cells do not.

We can use this difference to detect tumor cell DNA (**ctDNA**) in a blood sample.

ctDNA
circulating tumor
deoxyribonucleic acid

Presence of ctDNA may mean different things for different people.



What does my result mean for my cancer?
We want to know, too!

- ctDNA may help us better understand what a tumor is doing in the body
- ctDNA may help us understand if a treatment is working or if it needs to be changed
- ctDNA may be a useful indicator that the tumor is growing or spreading
- The sooner we can detect changes, the sooner we may be able to act

There is still much to learn about ctDNA!
You can help us through participation in cancer research! ***Study details below(?)***
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.

+ study details or follow up contact info?

NSIVE

Original 1 pager and 2 edits (June 2025)

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Could a blood test help us detect cancer?

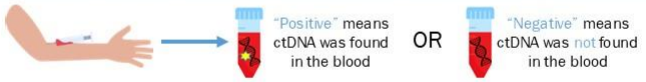
Similar to how we use a blood test to detect presence of cholesterol or blood sugar, we may be able to use a blood test to detect cancer.
Much easier than a scan or a biopsy! ☺

A blood sample can contain healthy cells and tumor cells.
Both healthy cells and tumor cells have DNA – a genetic recipe.
However, tumor cell DNA has specific changes called mutations (✸). Healthy cells do not.

We can use this difference to detect tumor cell DNA (**ctDNA**) in a blood sample.

ctDNA
circulating tumor ← → deoxyribonucleic acid

Presence of ctDNA may mean different things for different people.



What does my result mean for my cancer?
We want to know, too!

- ctDNA may help us better understand what a tumor is doing in the body
- ctDNA may help us understand if a treatment is working or if it needs to be changed
- ctDNA may be a useful indicator that the tumor is growing or spreading
- The sooner we can detect changes, the sooner we may be able to act

There is still much to learn about ctDNA!
You can help us through participation in cancer research! *Study details below(?)*
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.

+ study details or follow up contact info?

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Could a blood test help us detect cancer?

Similar to how we use a blood test to detect presence of cholesterol or blood sugar, we may be able to use a blood test to detect cancer.
Much easier than a scan or a biopsy!

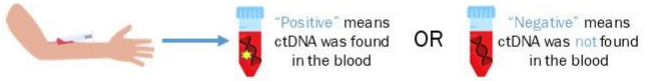
A blood sample can contain healthy cells and tumor cells.
Both healthy cells and tumor cells have DNA – a genetic code.

Tumor cell DNA has specific changes called mutations (✸). Healthy cells do not.

We can use this difference to detect tumor cell DNA (ctDNA) in a blood sample

ctDNA
circulating tumor ← → DeoxyriboNucleic Acid

Detecting ctDNA in a blood sample may mean different things for different people.



What does my result mean for your cancer?

- It may help us better understand what a tumor is doing in the body
- It may help us understand if a treatment is working or if it needs to be changed
- It may be a useful indicator that the tumor is growing or spreading

The sooner we can detect changes in ctDNA, the sooner we may be able to act

There is still much to learn about ctDNA!
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.
You can help us by taking part in a cancer research study!

Find a clinical trial at UNC Lineberger **Research For Me**

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

A ctDNA Blood Test for Cancer

Similar to how we use a blood test to measure cholesterol or blood sugar, we may be able to use a blood test to look for cancer.
This may be an easier and less expensive way to test for cancer.

A blood sample can contain DNA from healthy cells and tumor cells.
DNA is a set of instructions that tells your body how to grow, develop, and function.

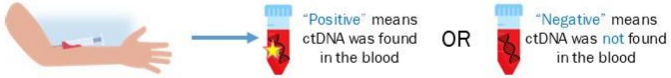
Tumor cell DNA has specific changes called mutations (✸)

The test looks for changes that are usually not found in healthy cell DNA

We can use these mutations to find circulating tumor cell DNA (**ctDNA**) in a blood sample.

ctDNA = circulating tumor DNA

What does the result mean?



Detecting ctDNA in a blood sample may have different uses.

- It may help doctors know if a treatment is working or if it needs to be changed
- It may be a useful test to show if the tumor is growing or spreading

Finding ctDNA in the blood may help your doctor tailor your treatment.

There is still a lot we need to learn about ctDNA.
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.
You can help future patients by taking part in a cancer research study.

Find a clinical trial at UNC Lineberger **Research For Me**

Some of the changes --- they do come up again!

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Could a blood test help us detect cancer?

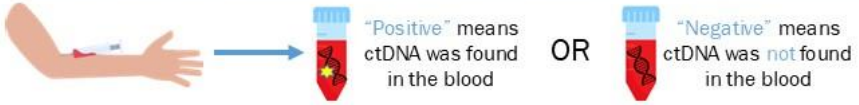
Similar to how we use a blood test to detect presence of cholesterol or blood sugar,
we may be able to use a blood test to detect cancer.
Much easier than a scan or a biopsy! ☺

A blood sample can contain healthy cells and tumor cells.
Both healthy cells and tumor cells have DNA – a genetic recipe.
However, tumor cell DNA has specific changes called mutations (✡). Healthy cells do not.

We can use this difference to detect tumor cell DNA (**ctDNA**) in a blood sample.

ctDNA
circulating tumor — deoxyribonucleic acid

Presence of ctDNA may mean different things for different people.



What does my result mean for my cancer?
We want to know, too!

- ctDNA may help us better understand what a tumor is doing in the body
- ctDNA may help us understand if a treatment is working or if it needs to be changed
- ctDNA may be a useful indicator that the tumor is growing or spreading
- The sooner we can detect changes, the sooner we may be able to act

There is still much to learn about ctDNA!
You can help us through participation in cancer research! *Study details below(?)*
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.

+ study details or follow up contact info?

Titles are always imp.

No smiley face.
Detect presence to measure
Detect to look for
Added cost

Lots of discussion

DNA is commonly known

Make syringe more visible

Personalized

Simplified

Highlighted call to take part in a study

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

A ctDNA Blood Test for Cancer

Similar to how we use a blood test to measure cholesterol or blood sugar,
we may be able to use a blood test to look for cancer.
This may be an easier and less expensive way to test for cancer.

A blood sample can contain DNA from healthy cells and tumor cells.
DNA is a set of instructions that tells your body how to grow, develop, and function.

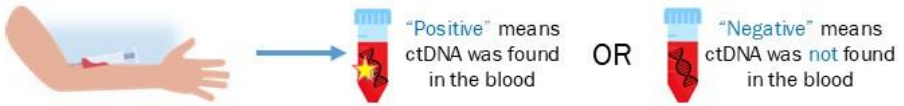
Tumor cell DNA has specific changes called mutations (✡)

The test looks for changes that are usually not found in healthy cell DNA

We can use these mutations to find circulating tumor cell DNA (**ctDNA**) in a blood sample.

ctDNA = circulating tumor DNA

What does the result mean?



Detecting ctDNA in a blood sample may have different uses.

- It may help doctors know if a treatment is working or if it needs to be changed
- It may be a useful test to show if the tumor is growing or spreading

Finding ctDNA in the blood may help your doctor tailor your treatment.

There is still a lot we need to learn about ctDNA.
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.
You can help future patients by taking part in a cancer research study.

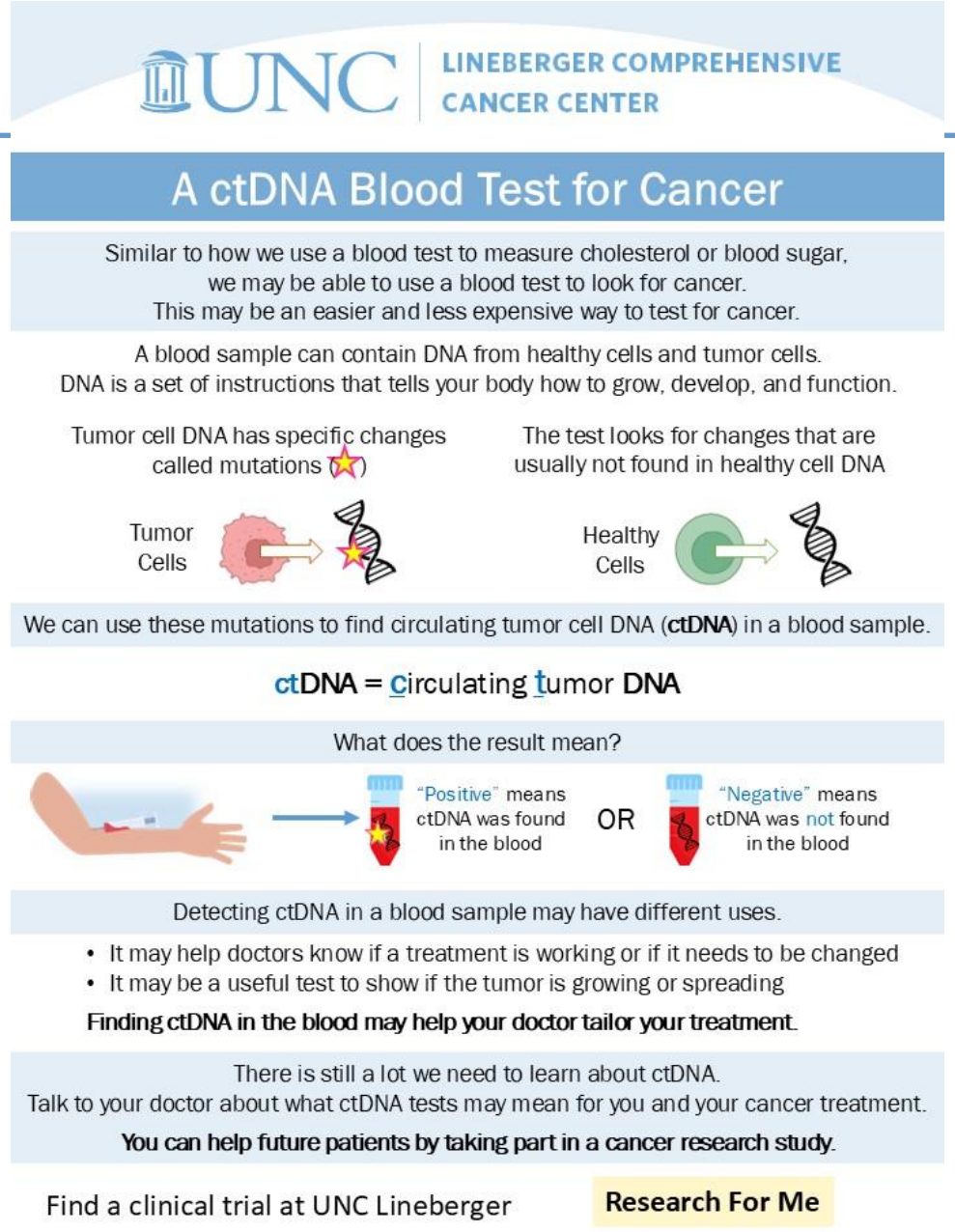
Find a clinical trial at UNC Lineberger **Research For Me**

Went out for review July 2025

Material	Date	Responses	Understandability questions Total #	Score 1=agree 0=disagree Range	Percent agree - average	Actionability questions Total #	Score 1=agree 0=disagree Range	Percent agree - average
ctDNA	07/2025	8	16	13-16	**93%**	5	0-5	**80%**
General Info	08/2025	7	16	13-16	**89%**	5	3-5	**91%**

Key comments:

- The only thing that may help is blocking an area with an outline to make it stand out more, perhaps the pictures or the ctdna test.
- A little more definition between sections might be good.
- The flyer feels somewhat cluttered due to the high volume of text in a limited space.
- Simplifying the content and incorporating more visuals could help highlight key messages more effectively. For example, the action statement "Find a clinical trial at UNC Lineberger" is easy to overlook, even though it appears to be the main goal of the flyer.



Added color and format (August 2025)

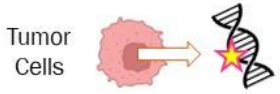
UNC | LINEBERGER COMPREHENSIVE CANCER CENTER

A Blood Test for Cancer?

Similar to how we use a blood test to measure cholesterol or blood sugar,
we may be able to use a blood test to look for cancer.
This may be an easier and less expensive way to test for cancer.

A blood sample can contain DNA from healthy cells and tumor cells.
DNA is a set of instructions that tells your body how to grow, develop, and function.

Tumor cell DNA has specific changes called mutations (★)

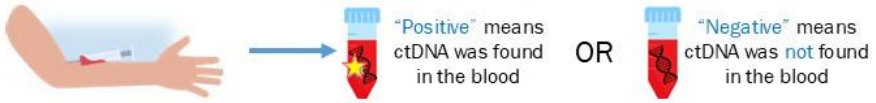


The test looks for changes that are usually not found in healthy cell DNA

We can use these mutations to find circulating tumor cell DNA (**ctDNA**) in a blood sample.

ctDNA = circulating tumor DNA

What does the result mean?



Detecting ctDNA in a blood sample may have different uses.

- It may help doctors know if a treatment is working or if it needs to be changed
- It may be a useful test to show if the tumor is growing or spreading

Finding ctDNA in the blood may help your doctor tailor your treatment.

There is still a lot we need to learn about ctDNA.
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.

You can help future patients by taking part in a cancer research study.

Find a clinical trial at UNC Lineberger go.unc.edu/LCCCResearchForMe

New Logo (February 2026)

Lineberger Comprehensive Cancer Center

A Blood Test for Cancer?

Similar to how we use a blood test to measure cholesterol or blood sugar,
we may be able to use a blood test to look for cancer.
This may be an easier and less expensive way to test for cancer.

A blood sample can contain DNA from healthy cells and tumor cells.
DNA is a set of instructions that tells your body how to grow, develop, and function.

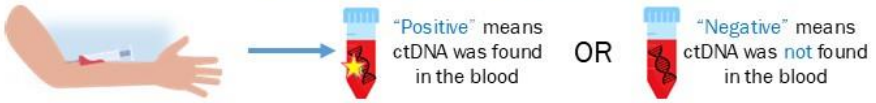
Tumor cell DNA has specific changes called mutations (★)

The test looks for changes that are usually not found in healthy cell DNA

We can use these mutations to find circulating tumor cell DNA (**ctDNA**) in a blood sample.

ctDNA = circulating tumor DNA

What does the result mean?



Detecting ctDNA in a blood sample may have different uses.

- It may help doctors know if a treatment is working or if it needs to be changed
- It may be a useful test to show if the tumor is growing or spreading

Finding ctDNA in the blood may help your doctor tailor your treatment.

There is still a lot we need to learn about ctDNA.
Talk to your doctor about what ctDNA tests may mean for you and your cancer treatment.

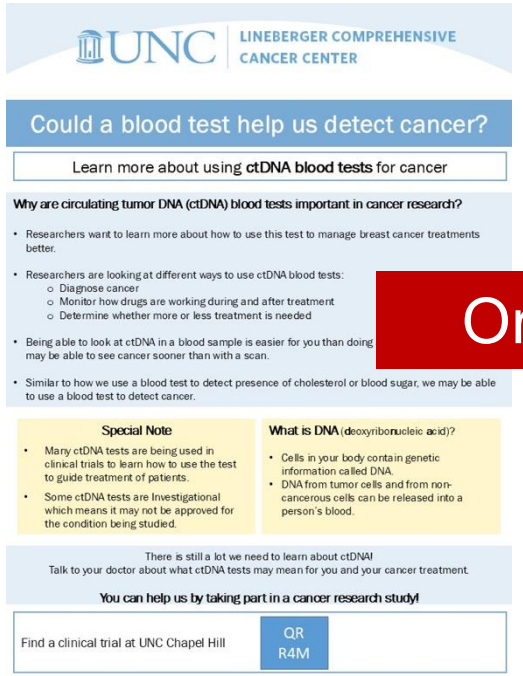
You can help future patients by taking part in a cancer research study.

Find a clinical trial at UNC Lineberger go.unc.edu/LCCCResearchForMe

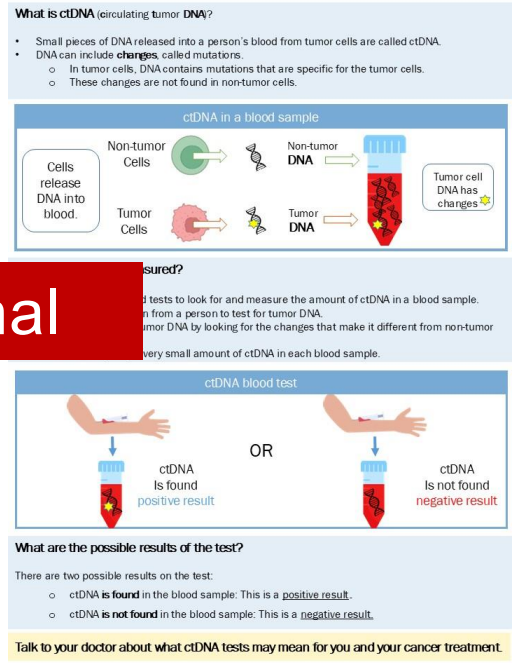
HENSIVE CANCER CENTER

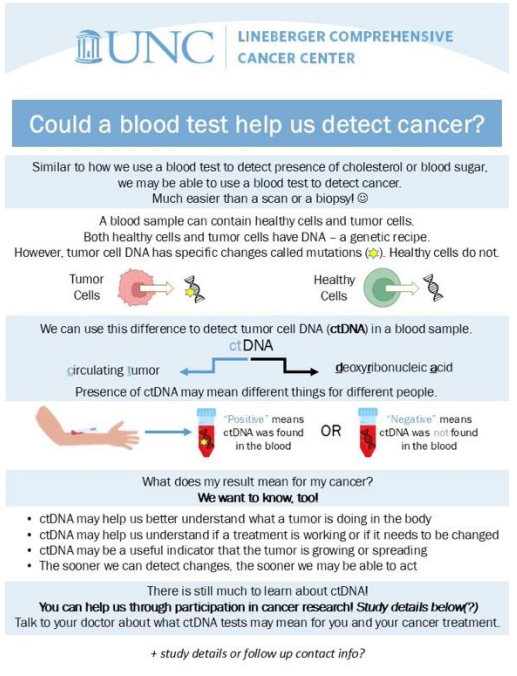
Final Process

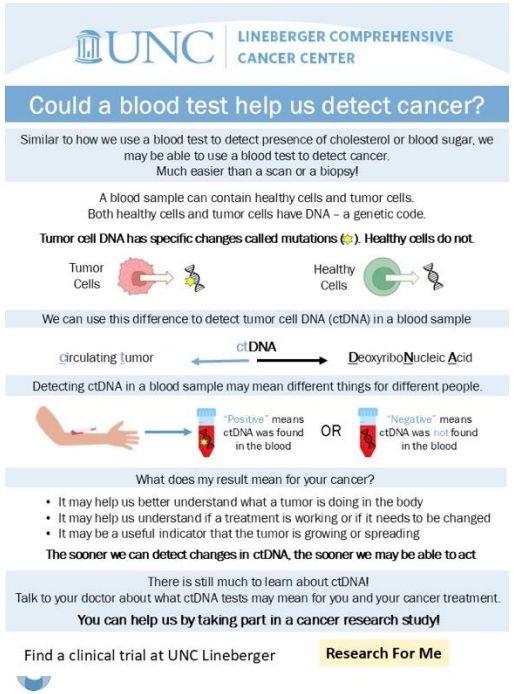
- Feb 2025 – 2pg
- Feb 2025 – 1pg
- March – June - edits
- July – reviewed PEMAT
- August – Final

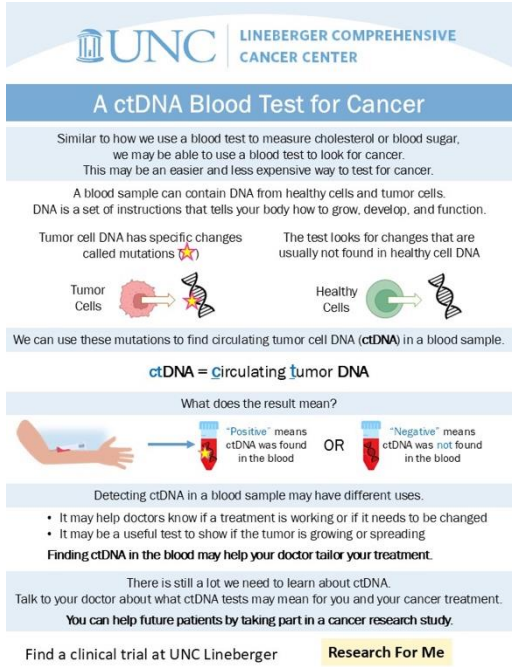


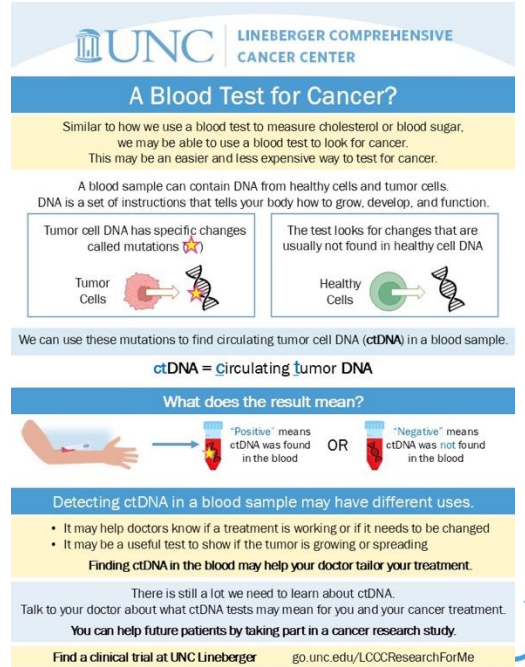
Original



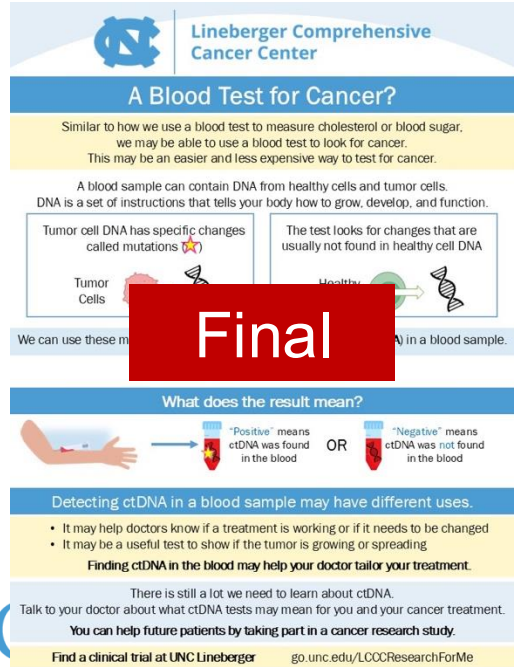








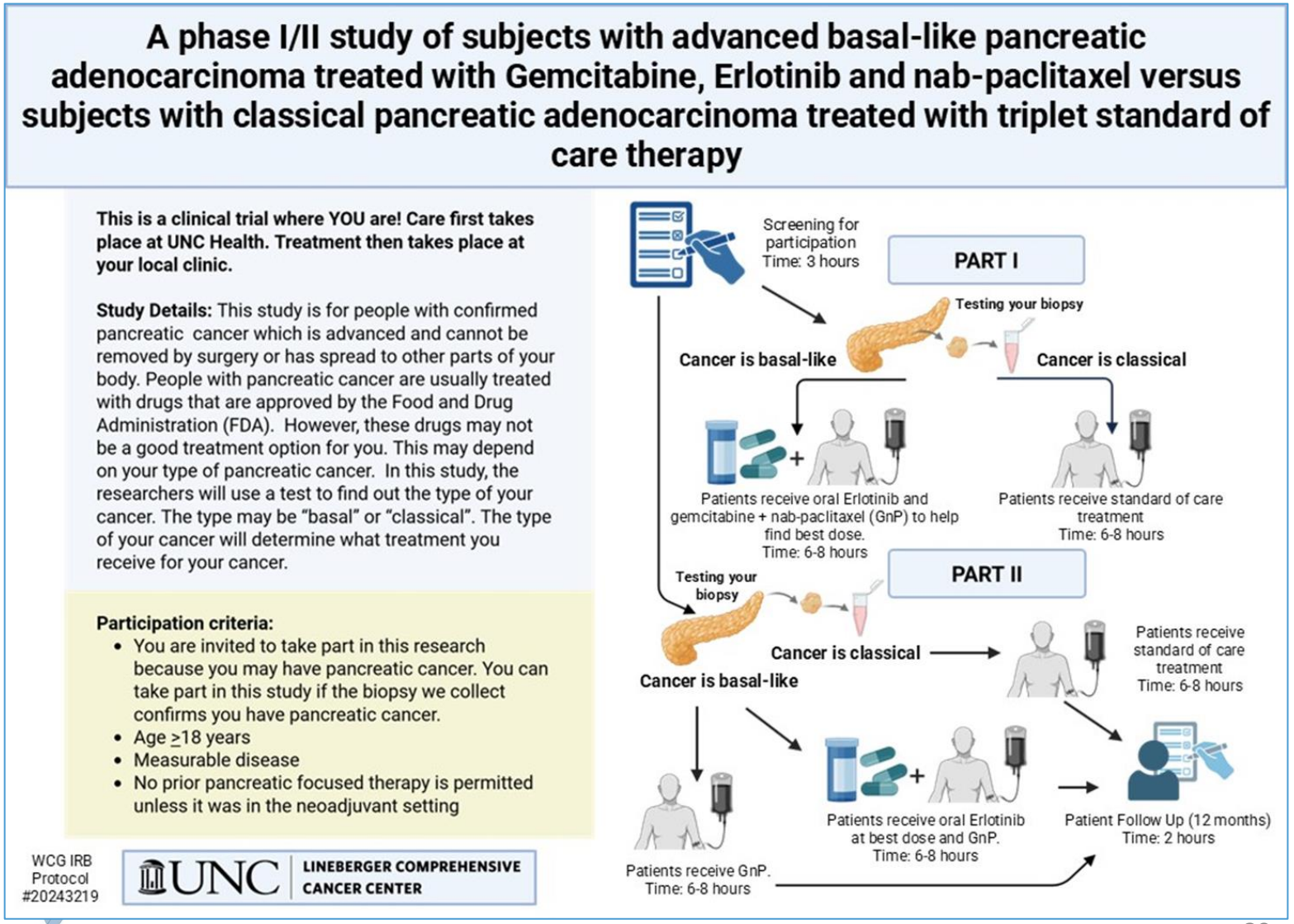
Final



Providing feedback on an Infographic

LCCC2220

An infographic



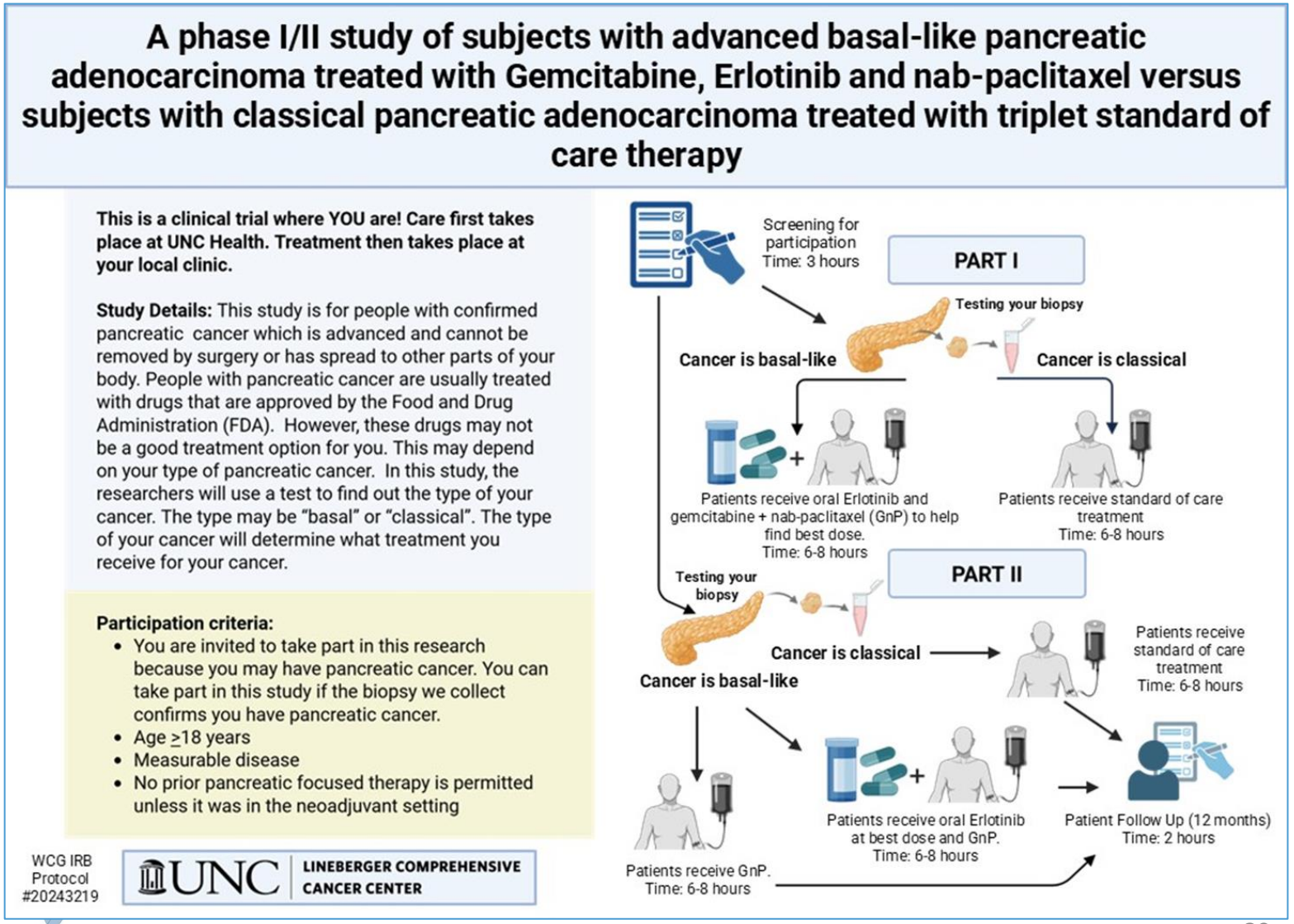
You are helping someone develop this info graphic.

What is your first Impression?

What would you edit or comment on?

- Visual overall
- Schema
- Verbiage

An infographic



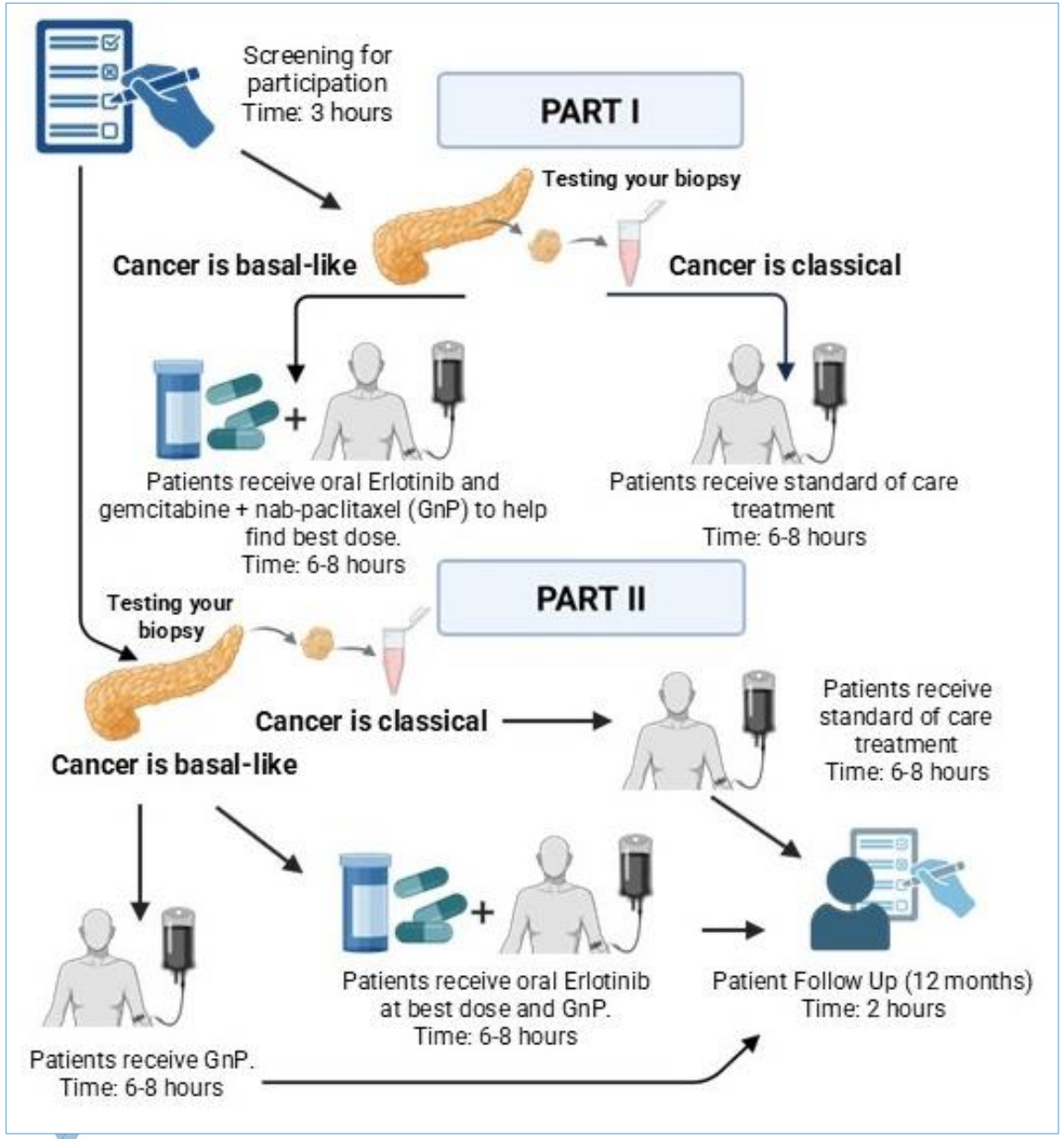
1st impression:

Too busy and not clear

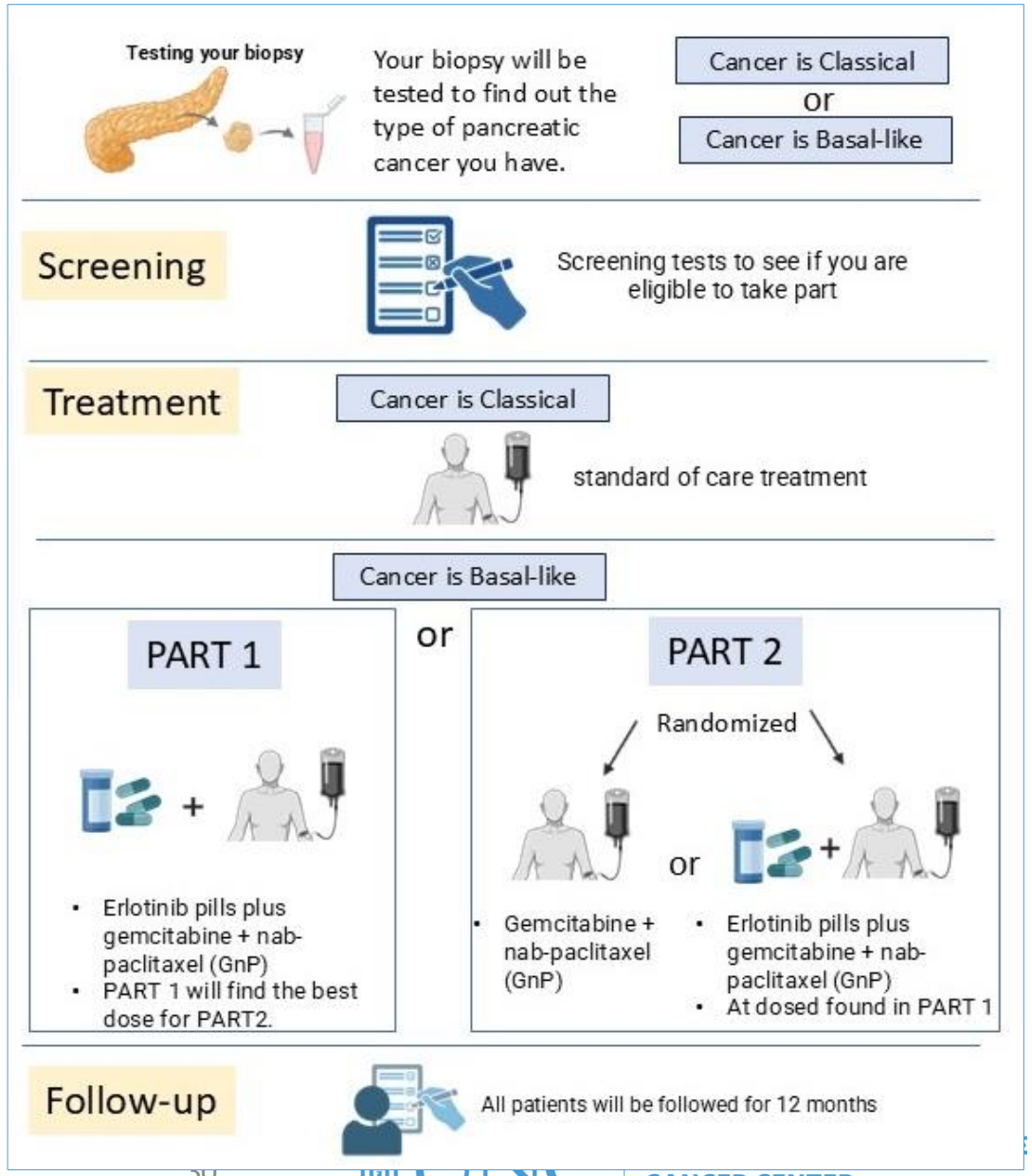
What would I edit?

- Shorten title
- Shorten text and make more understandable
- Try to figure out what the schema should be and edit that.

Original



Suggested Final

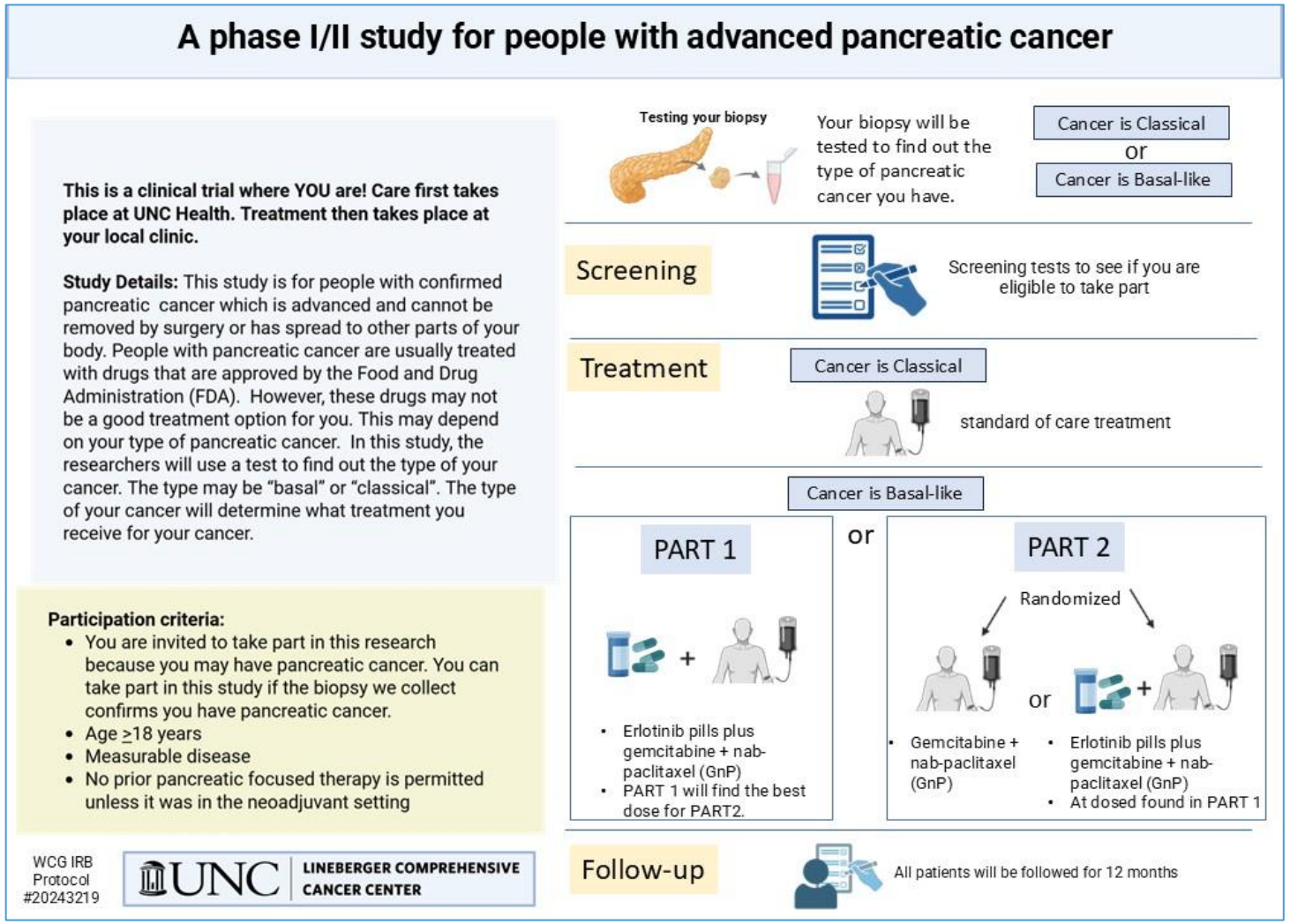


Changed Title

A phase I/II study of subjects with advanced basal-like pancreatic adenocarcinoma treated with Gemcitabine, Erlotinib and nab-paclitaxel verses subjects with classical pancreatic adenocarcinoma treated with triplet standard of care therapy

Shortened
Don't use 'subject'
Use cancer not adenocarcinoma
Delete details not needed

A phase I/II study for people with advanced pancreatic cancer



Documents you may be asked to review

- Consent Form
- Clinical trial Patient Materials
- Lay or public abstract
- Public summaries of results

Why your voice is needed

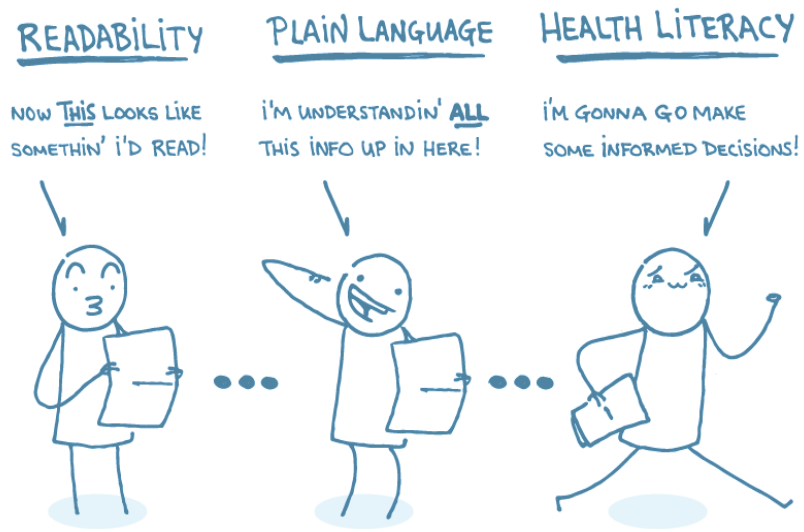
- Clear communication builds trust
- Materials need to be understandable and actionable
- Everyone can understand a clearly written document
- Ensure respect for the people reading the material

You can help researchers learn how to communicate in writing to the public.

Research

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Lay/Public Abstract



From Communicate Health

UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Purpose

Often required

To describe the project and its impact in plain language

Funders want to be able to tell donors/tax payers what they are funding and how it will help patients with cancer – make a significantt impact.

Content

Public summary should contain:

- Why is the research important to patients?
- What questions are being asked and answering?
- Why do you think this research will succeed?
- How will this research ultimately improve the lives of patients?

You can help researchers learn how to write a better public abstract.

EXAMPLE: Communicating through a public abstract

Guidance for Researchers: What should you include in your public abstract (summary)?

1. Why is your research important to patients?
2. What question are you answering?
3. Why do you think your research will succeed?
4. How will your research ultimately improve the lives of patients?

UNC | LINEBERGER COMPREHENSIVE CANCER CENTER

Writing a Lay/Public Abstract

A summary about your research…

- What do you hope to prove?
- Why is it important to patients?
- Why do you think it will work/be successful?
- How may it ultimately improve how people feel, function, or survive?

What You Need to Know

Think about your audience Use common, everyday words Keep it short and to the point	Avoid medical jargon and acronyms Keep sentences to less than 15 words and brief paragraphs. Split 1 long sentence into 2 short sentences
Organize and filter content Use clear descriptive headings Include only what your audience needs to know Use bulleted lists where practical	Start with a good title or short descriptive paragraph highlighting the importance of your research Use meaningful headings Logically walk the reader through your research
Other things to keep in mind Use complete sentences Use appropriate punctuation and grammar Spell check	Every sentence should have a noun and a verb Appropriate grammar makes it easier to read and understand Misspellings are not good
Writing about impact Be precise and specific How will your research improve the lives of patients If successful, will it lead to a solution for an overarching research challenge	Do not use vague words like impact and or affect It may take more than one sentence to be more specific Tell the reader why this research is important to this field of research

When you think you are done…

Proofread with fresh eyes

Read it aloud

Take it for a test drive – give it to a non-scientific person to read

Resources

Hemmingway – check for readability

Grammarly – check for readability

NCI Dictionary – definitions of common cancer terms

Spell Chexck

What You Need to Know

Think about your audience Use common, everyday words Keep it short and to the point	Avoid medical jargon and acronyms Keep sentences to less than 15 words and brief paragraphs. Split 1 long sentence into 2 short sentences
Organize and filter content Use clear descriptive headings Include only what your audience needs to know Use bulleted lists where practical	Start with a good title or short descriptive paragraph highlighting the importance of your research Use meaningful headings Logically walk the reader through your research
Other things to keep in mind Use complete sentences Use appropriate punctuation and grammar Spell check	Every sentence should have a noun and a verb Appropriate grammar makes it easier to read and understand Misspellings are not good
Writing about impact Be precise and specific How will your research improve the lives of patients If successful, will it lead to a solution for an overarching research challenge	Do not use vague words like impact and or affect It may take more than one sentence to be more specific Tell the reader why this research is important to this field of research

You are asked to review a document– what do you do?

Video Demo
8 minutes

Have your tools handy

Hemingway Editor

Hemingway Editor (hemingwayapp.com)

Copy/Paste into Hemingway ---
It shows you the 'problem areas'

NIH NATIONAL CANCER INSTITUTE
NCI Dictionary of Cancer Terms

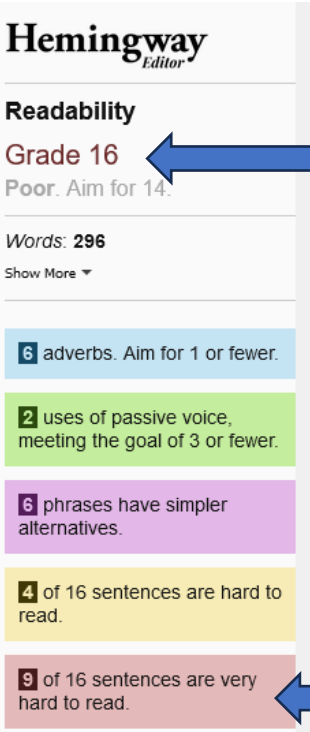
NCI Dictionary of Cancer Terms - NCI

MRCT MULTI-REGIONAL CLINICAL TRIALS
THE MRCT CENTER of BRIGHAM AND WOMEN'S HOSPITAL and HARVARD

Multi-Reginal Clinical Trials
Clinical Research Glossary

Ask for the scientific documents too (technical abstract, protocol, etc)

Inflammatory bowel diseases (IBD), notably Crohn's disease (CD), are chronic relapsing inflammatory disorders caused by aberrant immune responses to resident gastrointestinal (GI) microbes. Intestinal fibrosis is a significant complication in CD patients, causing severe intestinal strictures and obstructions that are ultimately relieved by surgical bowel resection. Mechanisms driving IBD-associated fibrosis are poorly understood but implicate the microbiome, especially adherent-invasive E. coli (AIEC). Previously, our work demonstrated that AIEC production of the siderophore yersiniabactin (Ybt) promotes fibrosis in a gnotobiotic Il10-/- mouse model. These pro-fibrotic effects did not require AIEC uptake/utilization of Ybt, suggesting direct effects on the host. Here we show that CD11b+ F4/80+ macrophages are abundant in the submucosa and muscularis of fibrotic lesions in IBD mouse models and human IBD patients. We hypothesized that Ybt targets host macrophages to drive fibrosis. HIF-1α activation is a critical for immune cell function in inflammation and can be activated by metal sequestration. We demonstrate that AIEC infection drives HIF-1α in macrophages, which is dependent upon Ybt production. In fibrotic lesions of IBD mouse models and human IBD patients, HIF-1α is activated and nuclear-localized to macrophages. We identify that zinc sequestration is responsible for HIF-1α activation, rather than canonical iron binding to Ybt. Furthermore, co-culture of macrophage and fibroblast cells reveal that AIEC infection induces pro-fibrotic genes, a phenomenon that requires AIEC, macrophages and fibroblasts interacting together. In the context of pro-fibrotic effects, NF-kB activation is necessary but not sufficient, whereas Ybt unilaterally serves as a trigger for HIF-1α activation. Collectively, these results suggest that as intestinal macrophages encounter AIEC, Ybt sequesters zinc, causes an accumulation of nuclear HIF-1α, and this imbalance of metal homeostasis drives pro-fibrotic macrophage and fibroblast activation. Ultimately, effective fibrotic remodeling fails and leads to intestinal fibrosis in IBD patients.



High reading level

RED is very hard to read

Complicated opening statement.

Jargon, complicated word
Simple definition needed

- **Inflammatory bowel diseases** (IBD), notably **Crohn's disease** (CD), are **chronic relapsing** inflammatory disorders caused by **aberrant** immune responses to resident gastrointestinal (GI) microbes. Intestinal **fibrosis** is a significant complication in CD patients, causing severe intestinal **strictures** and obstructions that are ultimately relieved by **surgical bowel resection**.

NOTE: The first sentence is important to engage and inform the reader!

Inflammatory bowel diseases (IBD), notably Crohn's disease (CD), are chronic relapsing inflammatory disorders caused by aberrant immune responses to resident gastrointestinal (GI) microbes.

Grade 21, ease of reading 0 (word)

Look up definition of IBD and CD from NCI Dictionary
Create an introduction explaining the disease first.

New Sentence:

Inflammatory bowel diseases (IBD) is an inflammation of the colon and rectum. Crohn disease (CD) is a type of IBD involving the small intestine and colon.

Grade 9.4, ease of reading 50 (word)

Inflammatory bowel diseases (IBD), notably Crohn's disease (CD), are chronic relapsing inflammatory disorders caused by aberrant immune responses to resident gastrointestinal (GI) microbes.

Grade 21, ease of reading 0 (word)

NOTE: There are 2 concepts left to explain – chronic/relapsing and aberrant immune response.
Split into separate sentences
Look up chronic, relapsing and aberrant for alternate wording
- Word thesaurus
- NCI dictionary

New Sentences:

IBD can last a long time and can come back often.
These diseases are caused by abnormal immune responses to resident gastrointestinal (GI) microbes.

Grade 8.2, ease of reading 57 (word)

Original:

Inflammatory bowel diseases (IBD), notably Crohn's disease (CD), are chronic relapsing inflammatory disorders caused by aberrant immune responses to resident gastrointestinal (GI) microbes.

Grade 21, ease of reading 0 (word)

Edited:

Inflammatory bowel diseases (IBD) is an inflammation of the colon and rectum. Crohn disease (CD) is a type of IBD involving the small intestine and colon. IBD can last a long time and can come back often. These diseases are caused by abnormal immune responses to resident gastrointestinal (GI) microbes.

Grade 8.8, ease of reading 53.7 (word)

Inflammatory bowel diseases (IBD), notably Crohn's disease (CD), are chronic relapsing inflammatory disorders caused by aberrant immune responses to resident gastrointestinal (GI) microbes. Intestinal fibrosis is a significant complication in CD patients, causing severe intestinal strictures and obstructions that are ultimately relieved by surgical bowel resection. Mechanisms driving IBD-associated fibrosis are poorly understood but implicate the microbiome, especially adherent-invasive E. coli (AIEC). Previously, our work demonstrated that AIEC production of the siderophore yersiniabactin (Ybt) promotes fibrosis in a gnotobiotic Il10-/- mouse model. These pro-fibrotic effects did not require AIEC uptake/utilization of Ybt, suggesting direct effects on the host. Here we show that CD11b+ F4/80+ macrophages are abundant in the submucosa and muscularis of fibrotic lesions in IBD mouse models and human IBD patients. We hypothesized that Ybt targets host macrophages to drive fibrosis. HIF-1α activation is a critical for immune cell function in inflammation and can be activated by metal sequestration. We demonstrate that AIEC infection drives HIF-1α in macrophages, which is dependent upon Ybt production. In fibrotic lesions of IBD mouse models and human IBD patients, HIF-1α is activated and nuclear-localized to macrophages. We identify that zinc sequestration is responsible for HIF-1α activation, rather than canonical iron binding to Ybt. Furthermore, co-culture of macrophage and fibroblast cells reveal that AIEC infection induces pro-fibrotic genes, a phenomenon that requires AIEC, macrophages and fibroblasts interacting together. In the context of pro-fibrotic effects, NF-kB activation is necessary but not sufficient, whereas Ybt unilaterally serves as a trigger for HIF-1α activation. Collectively, these results suggest that as intestinal macrophages encounter AIEC, Ybt sequesters zinc, causes an accumulation of nuclear HIF-1α, and this imbalance of metal homeostasis drives pro-fibrotic macrophage and fibroblast activation. Ultimately, effective fibrotic remodeling fails and leads to intestinal fibrosis in IBD patients.

Bold Italic H1 H2 H3 Quote Bullets Numbers Link

and rectum. Crohn disease (CD) is a type of IBD involving the small intestine and colon. IBD can last a long time and can come back often. These diseased are caused by abnormal immune responses to resident gastrointestinal (GI) microbes. Intestinal fibrosis (forming fibrotic lesions) is a significant complication of CD. These fibrotic lesions can cause severe intestinal strictures (narrowing) and obstructions. These complications can eventually be corrected by surgical to remove the part of the intestine that is affected. How IBD-associated fibrosis is formed is poorly understood. The microbiome may be involved. the intestinal microbiome is the microorganisms and viruses that live in the intestinal tract. One microbe of interest is adherent-invasive E. coli (AIEC). Previously, we showed that AIEC produces a molecule called iderophore yersiniabactin (Ybt). We also showed that Ybt promotes fibrosis in mice. These pro-fibrotic effects did not require AIEC uptake/utilization of Ybt, suggesting direct effects on the host. Here we show that certain macrophages (a type of blood cell) are abundant in the fibrotic lesions in IBD mouse models and patients with IBD. We hypothesized that Ybt targets host macrophages to drive fibrosis. HIF-1α activation is a critical for immune cell function in inflammation. HIF-1a can be activated by metal sequestration (removal). We show that AIEC infection drives HIF-1α in macrophages, which is dependent upon Ybt production. In fibrotic lesions of IBD mouse models and patients with IBD, HIF-1α is activated and found in macrophages. We found that zinc sequestration is responsible for HIF-1α activation. Furthermore, growing macrophage and fibroblast cells together with AIEC causes an increase in pro-fibrotic genes. This requires that AIEC, macrophages and fibroblasts interact together. In the context of pro-fibrotic effects, NF-kB activation is necessary but not sufficient. However, Ybt alone serves as a trigger for HIF-1α activation. Together, these results suggest that as intestinal macrophages encounter AIEC, Ybt sequesters zinc. This causes an accumulation of nuclear HIF-1α. This imbalance of metal balance drives pro-fibrotic macrophage and fibroblast activation. Ultimately, the failure to control fibrosis can lead to intestinal fibrotic lesions in patients with IBD.

Write Edit

Hemingway Editor

Readability

Grade 10

OK. Aim for 9.

Words: **355**

Show More

3 adverbs. Aim for 1 or fewer.

7 uses of passive voice. Cut to 6 or fewer.

6 phrases have simpler alternatives.

7 of 31 sentences are hard to read.

1 of 31 sentences is very hard to read.

? What are some common ‘issues’ you see when you have edited a material meant for the public

Format →

Do this

The cell was hypermethylated and as a result transcription was affected.

NOT this

The cell was hypermethylated and as a result transcription was affected.

Left/right justification is hard to read and edit! Science has big words!

Verbiage → Jargon

resection is surgery

Process → Not enough time to review

Clearly communicate – some tips

What do they want to know about?

- Use tools and resources like hemingway, word, NCI
- Is the material appropriate for the audience? Tailor the message to them
- Keep it simple, but not simplistic, use common words
- Logically walk someone through the information
- Compare to something common metaphors or analogies
- Practice!! The more you review the easier it gets!

Letter of Support

Your attention to the letter of support can help a grant succeed

Letter of Support

Purpose

Often required

To demonstrate your enthusiasm and support

To strengthen the application by providing the advocate perspective on why the research is important to patients

Content

the content of your letter is tailored to the project you are supporting.

It is not necessary to include every item in the template, just the items that are relevant to the project you are supporting.

You can ask the researcher to provide a draft letter for you to edit and fill in your personal information.

Tips about Format

- ✓Use personal letterhead if you have it. If not, **include your name, address, phone # and email address** at the top right or bottom (under your signature) of your letter.
- ✓Ask if there is a page limit. If there is no page limit, **stay within 1-2 pages**, include page number if it is more than one page.
- ✓**Date** the letter
- ✓**Address the letter to the funder or to the researcher** (depends on application instructions), but either is usually OK.
- ✓**Sign** the letter.
  - ✓ Insert a 'picture' of your signature. (sign a piece of paper, take a photo of it with your smartphone, insert the photo (.jpg) as your signature. Send your signed letter back to the researcher (.doc or .pdf)
  - ✓ Print, sign and scan to send pdf back to the researcher

Parts of the Letter of Support

Introductory Paragraph

- Include the name of the researcher and the title of the application.
- Indicate your commitment to serving as an advocate on the research project.

Body of the Letter

- Talk about your advocacy, why you are the best fit for this project
- Talk about the research, it's importance to patients
- Explain interaction with the researcher
- Your role if the project is funded – needs to match grant

Closing Paragraph

- Restate why you believe that the research should be conducted and why is should be funded
- Restate your commitment to support and collaborate with the researcher on the project
- Thank the funder for their consideration of the application

Impact Statement

Purpose

Often required

Grants usually have a section on impact, or how it will eventually help patients.

Content

- Convey who may benefit and how they benefit because of the project's success.
- Why is this significant?
- Is this project filling a knowledge gap? Treatment gap?
- How will this research ultimately improve the lives of patients?

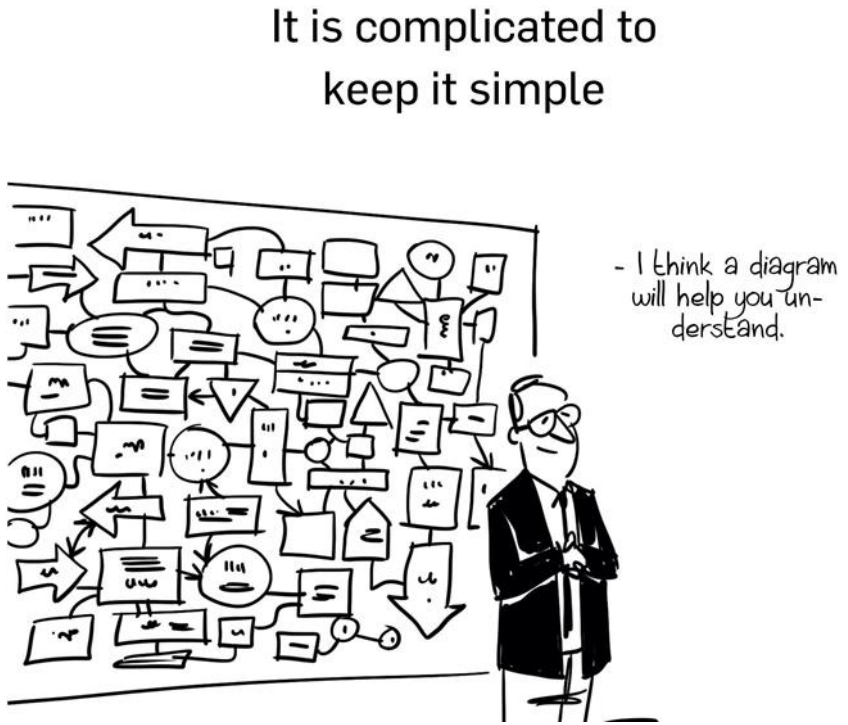
With your experience you can help make this section more meaningful to patient reviewers and funders.

Communicating impact – you can help

- What should be avoided when writing or speaking about how research will ‘impact’ patient?

What is a good ‘impact statement”?

It’s complicated



Avoid using the words “Impact” and “Affect”

- Avoid using impact **and affect b**ecause they are vague and consequently unclea**r** by themselves they don’t mean anything in particular
- **Use more precise words (verbs)**

✗

Dr. Jones
had an impact on medicine.

→

Dr. Jones
influences women to enter the field of medicine

✓

✗

The policy will
affect the amount of paperwork required

→

The policy will
increase paperwork.

✓

My suggestions for a good impact statement

- Describing impact to patients is not just one sentence
- Don't be vague

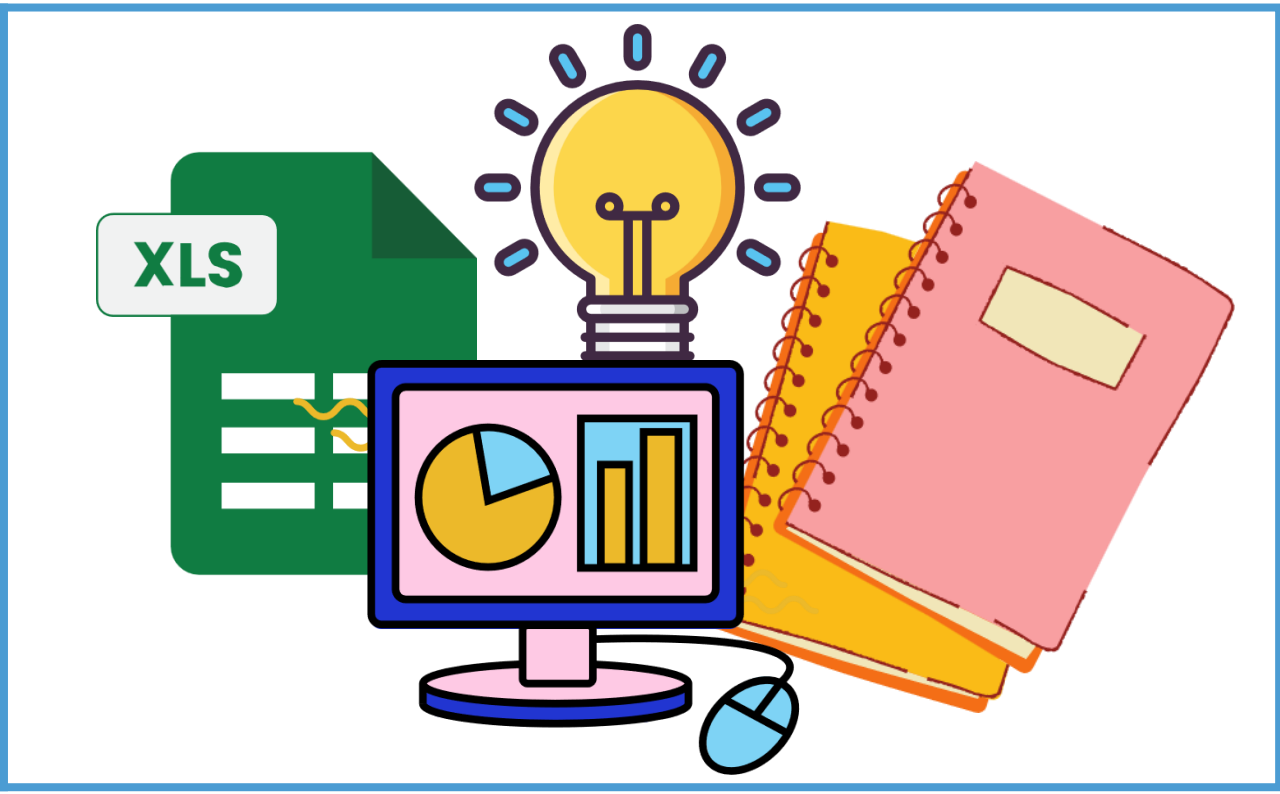
> *'The results from this research will lead to new drugs to treat triple negative breast cancer'*

- Be specific

> *'…this will be an oral drug which will reduce the cost for patients by decreasing clinic visits',*
>
> *'… is more specific to the target which has the potential to have fewer side effects when given to patients.'*

- Show that you care and are excited to do research that will improve the lives of cancer patients

Resources



Resources (1/2)

Readability

- ❑ Grammarly or Hemingway, an app for readability and grammar.
- ❑ How to turn on Microsoft Word's Flesh Kincaid Readability Statistics.
- ❑ Readable's What is Flesh Kincaid Readability?
- ❑ Quick Read on the order of text.
- ❑ This LinkedIn Learning on Plain Language (42 min)

Plain Language

- ❑ NIH Plain Language Training - website
- ❑ History of Plain Language in the US Government (Plain Language Act of 2010)
- ❑ CDC's Clear Communication Index.
- ❑ Plain Language Medical Dictionary. UM's thesaurus style live search on ways to explain big medical words.
- ❑ Real Life Research ICF Edited- Sample Paragraphs.

Relatability & Inclusivity

- ❑ Article on Content being Inclusive, Accessible, Fun.
- ❑ Quick Read on Cultural Competence
- ❑ Quick Read on 'Target Audience'
- ❑ Website: EthnoMed-Integrating Culture into Clinical Practice.
- ❑ Perspective piece on Shame in Physician-Patient interaction by Harris & Darby (2009)
- ❑ This article on Equitable and Empowering Language in Grant Writing (2020)
- ❑ This publication on Words Matter: Use of Respectful Language in Oncology (2021)

Resources (2/2)

Health Literacy

- ❑ Publication on Health Literacy for Healthy People 2030 (Nov 2021)
- ❑ Publication on Health Literacy gaps between Physicians and Patients.
- ❑ UNC's Health Literacy Library Guide
- ❑ CDC's Health Literacy Comprehensive Guide
- ❑ Journal of Public Health Management & Practice's Podcast on Health Literacy (Apr 2021)
- ❑ Boston University's Database of Validated Literacy Tests by Disease Type.
- ❑ National Center for Education Statistic's Interactive Literacy Maps, the key for literacy and numeracy.

Oncology Resources

- ❑ National Read on 'Palliative Care'
- ❑ Quick Reads on Screening vs. Testing and Positive vs. Negative Results.
- ❑ Quick Read on Cancer terminology
- ❑ Quick Read on User Testing Materials, on a budget.
- ❑ JAMA Oncology's Publication on Battle w/ Cancer.
- ❑ NCI's Dictionary of Cancer Terms
- ❑ Unsplash: Database of free Stock Photos.
- ❑ Publication on Biobanking Recruitment Preferences of rural communities.
- ❑ Publication on Predictors of biospecimen donation (time spent w/ MDs and religion!)
- ❑ Publication on Biobanking of pediatric samples and reconsent in adulthood.
- ❑ Publication on how analogies and metaphors work in oncology communications.

THANK YOU

Learning Together

ASPIRE

Advocates & Scientists Partner in Research Education

Laurie Betts, PhD
UNC Lineberger Patient Advocates for Research Council (**PARC**)

LEAP

Lineberger Excellence in Advocacy Program

Learning Together

ASPIRE

Advocates & Scientists Partner in Research Education

Patty Spears
Patient Advocates for Research Council (**PARC**)
paspears@med.unc.edu

Jennifer Potter
Lineberger Excellence in Advocacy Program (**LEAP**)
jpotter4@med.unc.edu

Veronica Carlisle
Community Advisory Board (**CAB**)
veronica_carlisle@med.unc.edu

Laurie Betts
Advocates & Scientists Partner in Research Education (**ASPIRE**)