Lay Summary Guide for Researchers: Tips on Writing a Lay Summary

There are several key elements of developing a lay summary for researchers to consider:

1. *Structure and content*
2. *Readability*
3. *Language Guide*

1. Structure and Content

Using plain language, answer these questions as a general guide to form your lay summary:

- What is the research question?
- Why are you asking the question?
    - Describe how the study addresses a relevant evidence gap in the tumour type or more broadly
    - How and what types of patients with cancer would be affected by this research?
    - Why is the study needed? Highlight the direction of the research and how it may contribute to the broader knowledge base of cancer
- What will you do to find the answer?
    - Describe the study methods, tools, setting and the patient population
    - Study duration
- What do you expect to find?
    - What are the expected outcomes and timeframes
- Why do the anticipated findings matter?
    - The potential applications of the research
    - The relevance and benefits of the research e.g., to the wider population, to the quality of life, health and care of cancer patients current and future
    - Contributing to the body of knowledge about cancer
- How do you plan to use the findings?
    - Funding applications, evidence building, further collaborations, publication etc

2. Readability

- Develop the language in your lay summary as if you are describing the study to someone outside your field

- Define any technical terms used, such as “genome sequencing techniques” or “analytical tools”
- Refrain from using acronyms, but if necessary, spell out in full when first used in the text
- Refrain from using jargon or meaningless terms and phrases
- Choose appropriate verb choices such as simpler “buy” in place of “purchase”
- Provide simple, relevant examples when describing the research
- Have a word count of 250 words maximum. The minimum word count is 100 words
- Utilize an online readability tool such as www.readabilityformulas.com. This free tool has an automatic readability checker that analyzes your text (in a few seconds) and calculates the number of sentences, words, syllables, and characters in your content. Using readability formulas will yield the reading age level and grade level of your text and help you determine the suitability of your text to your audience. The reading grade level to be aimed at for the lay summaries is grade 8 or 9.

3. Language Guide

- Talk in an active voice (“I.. we..”) and second person in place of third person
- Use people-first language, ideally by focusing on the person, not the disease or circumstance, for example, use “people with cancer” or “treatments that have failed patients” rather than “patients who failed treatments”
- Try to avoid emotive or negative language such as battle, fight etc
- Be respectful
- Be realistic in your language around impact and expected outcomes. Please avoid detailing intensively the anticipated impacts and exaggerating benefits.

Lay Summary Before and After Examples

Example 1

Lay Summary

This project comprises a focused effort to understand the evolution of prostate cancer. It will provide a detailed understanding of the molecular heterogeneity of the disease, link that heterogeneity to clinical outcome, and develop improved clinical tools for patients and clinicians. By making all data and tools available, it will create key resources for community use. ICGC controlled-tier data will be used to probe the relationship of inherited genes to prostate cancer evolution and clinical behaviour.

Word count: 76 words
Readability: ***Grade Level 15, College graduate and above***

Revised Lay Summary

Prostate cancer begins when cells in the prostate gland start to grow out of control. This is caused by changes in the DNA of normal cells. DNA is the chemical in our cells that makes up our genes. Genes control how our cells work. We know that cancer can be caused by DNA mutations or changes. This can then lead to uncontrolled cell growth.

DNA changes can be inherited from a parent or acquired during a person's lifetime. We want to learn about when and how this happens in different people. By studying gene changes, we can help scientists to better understand how prostate cancer develops. This could help to design treatments that target those changes.

An organization called the International Cancer Genome Consortium (ICGC) has gathered data or information about the nature of various cancers. We want to study this data using powerful computers to learn about the growth and spread of prostate cancer. We want to see how certain genes are linked to prostate cancer and how our bodies react when gene changes occur.

We think that prostate cancer tumors are made up of many different types of cells. We want to know how these cells are linked to cancer treatments and outcomes. If we can see how these cell types respond to different treatments, we can find better ways to detect and treat prostate cancer. We can then add our new data to the ICGC database for use by patients and doctors in our communities.

Word count: 250 words
Readability: ***Grade 8***

Example 2

Lay Summary: Genome Architecture in Cancer

Cancer is often linked with acquired abnormalities of the tumor genome, such as mutations, gains and losses of parts, and other aberrant structures. Some tumors are characterized by an increased rate for such abnormalities, a process named genomic instability. Our research project is devoted to unraveling the origins of genomic instabilities in cancers. Our approach consists in the systematic analysis of cancer genome architecture with relation to the genes altered in various types of cancer. By analyzing ICGC controlled data, we aim at deciphering associations and functional links between gene alterations and the genomic instability patterns. Taking into consideration genomic instability could improve tumor molecular classifications, prognosis and prediction of response to treatment.

Word count: 113
Readability: ***Grade level 16, College level and above***

Rewritten Lay summary

Your genes carry all the information that makes you who you are. For example, they tell your body to have blonde hair or brown eyes. They also tell your cells how to behave, when to grow and when to die. It is usual for cells to repair faults in their genes. When the damage is very bad the cell may self-destruct or the immune system may recognise these cells as abnormal and kill them. This important mechanism helps to protect us from cancer.

Sometimes mutations in genes cause a cell to no longer understand instructions. The cell can then start to multiply out of control. It doesn't repair itself properly, and it doesn't die when it should. This can lead to cancer. Some genes have a tendency to develop mutations at a faster rate than other genes, and this is called genomic instability.

We don’t know why this happens, and the aim of our study is to understand why some genes mutate and change at a faster rate than others.

An organization called the International Cancer Genome Consortium (ICGC) has gathered data about the genomics of various cancers. Using powerful computers we plan to study and analyse the data that has been gathered on these types of fast mutating genes (genomic instability). This study will help us to understand more about the origins and patterns of genomic instability, and this in turn could help us to improve how patients respond to treatments in the future.

Word Count: 246
Readability: ***Grade 9***

Process to Edit

1. Fill in the table below with concepts from the original lay summary/abstract.

Example of Content Development using Example 1 - Lay Summary.

Question	Content
Research question?	To understand evolution of prostate cancer
Why ask?	Gain understanding of progression/growth/change over time Develop improved clinical tools for patients and clinicians
What to do to answer?	Use ICGC controlled tier data – clean, linkages, analysis Probe relationship of inherited genes to prostate cancer evolution and clinical behavior
What do you expect to find?	Detailed understanding of molecular heterogeneity of disease How heterogeneity is linked to clinical outcome
Why do findings matter?	Develop improved clinical tools for patients and clinicians
How to use findings?	Make all data and tools available Create key resources for community use

2. Write Draft 1 using answers to each question.

3. Using https://readabilityformulas.com/free-readability-formula-tests.php paste a sample of plain text abstract in the box.

4. Identify all words 3 or more syllables long (.g., Use **Show Word Statistics: 3+ syllable words (show all 'hard' words)** for substitution.

5. a) Substitute simple words or phrases found by checking word synonyms, b) Use simple explanations for complex words or phrases and/or c) Read similar concepts on lay websites.

6. Write Final version by making edits as needed to comply with word count, language and readability guidelines.