

Writing 'Plain Language' Summaries

Guidance for Researchers March 2014

Purpose

It is important to be able to speak or write about research in a way that funders, supporters, policy makers, consumers and the community can understand.

This document will help researchers applying for funding from Cancer Council WA to write good plain language summaries for their applications, and researchers who have received funding to write good plain language reports.

What is a plain language summary?

A plain language summary – sometimes called a lay summary or media summary – is a brief outline of a research project or research proposal that has been written for the public, rather than researchers or professionals. A plain language summary is not an attempt to 'dumb down' scientific information. It helps make information about research more open, transparent and accessible.

Writing in plain language may not come naturally to researchers, clinicians and scientists. However, we need to have this information so we can continue to fund research. There are a number of resources on writing in plain language available to researchers (see references and links in Appendix 1) and we are keen to support this area of work.

If you can describe your research to your relatives – and they understand what you do – you can write a plain language summary. It just requires a different way of writing.

How does Cancer Council WA use plain language summaries?

Plain language summaries are an important resource for us. We use plain language summaries of research:

To decide what research to fund

Our research committees include consumer representatives (people with experience of cancer or of caring for someone with cancer), as well as researchers from many different cancer-related disciplines. Plain language summaries of research proposals help all committee members to understand the research that is being described and allow them to make informed decisions about what to fund.

To let donors and supporters know how their money is being used

Our research grants program is funded through the support and generosity of our donors, corporate partners and supporters. We need to be able to describe the research we fund to a wide audience. Plain language summaries and reports help us to do this accurately. We also often provide them to our donors and supporters.

For new fundraising and marketing activities

We use plain language summaries and reports to develop fundraising and marketing communications – including media releases – about the research we support. Plain language summaries for all our funded projects are published on our website and in our annual Research Program booklet. This is a good way to promote our work and to attract more funds.

To show the impact of what we are funding

It is becoming increasingly important for charities to measure their impact and to demonstrate public benefit in a structured way. Plain language summaries of completed research projects or publications allow a wider audience to understand how the research we fund is making a difference.

What is the right level for a good plain language summary?

Lay audiences are diverse. The key is to strike a balance between superficial descriptions and those that are too detailed and complex. For example, saying 'this research aims to identify the proteins that do all the damage' is too simple but a statement like 'this research aims to identify the downstream signalling events following activation of molecule X' is too complex.

Tips on content and structure

Cancer Council WA grant applications require a short plain language description of the project. As a guide, it should be under 1000 characters in length, not including spaces and line breaks. This is a guide not a set limit as occasionally a particularly complex project may require more to be explained clearly.

Your plain language summary should include:

- Aims and purpose of the research
- An explanation of the type of cancer you are investigating and its impact
- How you will do the research
- What the benefits of the research will be

Start with the problem your research aims to solve, so the reader can identify with this first. Try to explain your research in 25 words and then use this as your first sentence.

Set the scene carefully, and explain how your work fits into the bigger picture.

Give the reader a reason to care about what you do. Address the 'so what?' by explaining how your work will help people affected by cancer, even if this is a long way off.

Leave 'white space' – use short paragraphs with at least one line space in between.

Our progress and final grant reports should also be written in plain language suitable for a lay audience. These don't have the same length restrictions as the application plain language summaries, but we encourage you to follow the same general principles.

Writing in plain language

Plain language – sometimes called plain English – means writing so the intended audience can read, understand and (if needed) act the first time they read it. It is important to minimise the use of jargon, technical terms and acronyms. If this is unavoidable, provide explanations.

Tips for writing in plain language:

- Write as if you were explaining your research to a friend or family member with no scientific knowledge or background.
- Use positive language.
- Keep your sentences short aim for an average sentence length of 15-20 words but use shorter sentences too.
- Use simple words and cut out unnecessary words.
- Use active rather than passive verbs.
- Don't turn verbs into nouns. For example, use 'converting' instead of 'the conversion of'.
- Use lists to help present ideas clearly.
- It can be helpful to use non-scientific analogies to explain complex ideas. For example 'Peripheral nerves work like power cables, carrying electrical signals from the brain to other parts of the body. The nerves are covered in a fatty layer called the myelin sheath much like the plastic insulating material covers electrical cables'.
- Ask at least one non-scientist to review your abstract and point out phrases or concepts they don't understand.

There is a list of words or phrases to avoid, with alternatives, in Appendix 2.

Final checks before submission

Before submitting your plain language summary or report we recommend checking the following points: ☐ Have I explained any acronyms I've used? ☐ Have I avoided using jargon or technical words where possible (see lists of alternatives)? ☐ If I have had to use jargon or technical words, have I explained them in plain language? ☐ Have I kept sentences short? ☐ Have I kept paragraphs short? ☐ Have I left white space between paragraphs? ☐ Have I talked directly to the reader (using 'you' and 'we') rather than 'third person scientific'? ☐ Have I used active rather than passive verbs? ☐ Have I included the 'so what?' of my research? ☐ Have I kept to any word limits? And most importantly: ☐ Have I given my plain language summary / report to a non-scientist (e.g. a friend or family member) to check they understand it?

This document has been adapted from the Association of Medical Research Charities, 'Writing Lay Summaries: Guidance for Researchers', October 2011.

Appendix 1: References and useful links

General Guidance:

- Association of Medical Research Charities, 'Writing Lay Summaries: Guidance for Researchers', October 2011,
- Digital Curation Centre. How to write a lay summary.

 http://www.dcc.ac.uk/resources/how-guides/write-lay-summary
- This publication has information, guidelines and resources for writing lay summaries.
- Bournemouth University Research Blog.

http://blogs.bournemouth.ac.uk/research/2011/06/15/writing-a-lay-summary-is-easy-right/

- Government of South Australia. 'Plain language.
 https://www.accessibility.sa.gov.au/your-role/content/plain-language
- McKenzie, A. 'Consumer and Community Participation Fact Sheet M11: Plain Language Summaries', Involving People in Research, 2011.

 https://www.involvingpeopleinresearch.org.au/wp-content/uploads/2018/08/fact_sheet_M11_plain_language_summaries.pdf
- The Plain English Campaign free guides, http://www.plainenglish.co.uk/free-guides.html
- Ridpath, JR, Greene, SM & Wiese, CJ. PRISM Readability Toolkit (3rd ed). Group Health Research Institute, Seattle, 2007.

 http://prism.grouphealthresearch.org/documents/PRISMReadabilityToolkit_ThirdEdv6_062210.pdf
- Imperial College London , Guide to writing a lay summary, 2018. http://wwwf.imperial.ac.uk/blog/fom/files/2018/05/Lay-Summary-v2018_PFDC.pdf

Lists of Technical Words with Plain Language Alternatives:

- Human Subjects Office, University of Iowa. 'Medical Terms in Lay Language', http://hso.research.uiowa.edu/medical-terms-lay-language#P
- Nancikevell, S. 'Plain Language Alternatives for Patient Information and Consent Materials'. Toronto, 2008.

 https://www.orpca.org/files/Plain Language Alternatives for Patient Information and Consent Materials.pdf
- Program for Readability in Science and Medicine (PRISM). 'Alternative Wording Suggestions' (extract from the PRISM Readability Toolkit). Group Health Research Institute, 2006.

http://prism.grouphealthresearch.org/documents/PRISM_alternative_word_list.pdf

Appendix 2: List of words and phrases to avoid, with alternatives, and ways to explain common technical terms

(Taken from Cancer Research UK's Writer's Guidelines, http://www.cancerresearchuk.org/cancer-help/utilities/about-cancerhelp-uk/cancerhelp-uk-policies/editorial-policy/writers-guidelines#words and the AMRC's 'Writing Lay Summaries: Guidance for Researchers', October 2011.)

If the word you're looking for isn't on this list, there are some very comprehensive alternative word lists for medical terms available on the internet. Some options are listed in Appendix 1.

- Accordingly so
- Affected (as in 'one affected lymph node') cancer in one lymph node
- Aggressive faster growing
- Anti-coagulation clinic blood clinic
- Apoptosis how cells die
- Arise from come from, or develop from
- Attend go to
- Chemotherapy regime chemotherapy drug combination or combination of chemotherapy drugs
- Consequently so
- Cosmetic result appearance after
- Defined as means
- Discontinue stop
- Discuss with talk to
- Drug target something in the body that is changed by a drug to give a
 desirable effect
- Duration time
- Efficacy of X how well X works
- Effective works
- End-point goal
- Experience (as in 'side effects you may experience') have
- Expression how genes make products (eg proteins) that can be used by cells
- For the purpose of to
- How effective it is how well it works
- If this is the case if so
- In combination with with
- Inform tell
- Initial first
- In other words so
- Insert put
- In spite of the fact that although
- In the event of if
- Lymph nodes affected by cancer lymph nodes containing cancer cells
- More effectively better (or works better than)
- Most appropriate best
- Mutation a sudden and permanent change in the genetic makeup of a cell
- Neurons nerves
- Occur happen
- Participate in take part

- Pathway a series of chemical reactions
- Positive lymph nodes lymph nodes containing cancer cells
- Prior to before
- Probability how likely X is to happen
- Progress (as in 'the cancer will progress') the cancer will grow...
- Proportion number
- Randomised-controlled trial a clinical trial where people are put into groups by chance. One group is given the best current treatment or a placebo and their progress is compared to people having the treatment that is being tested. People are usually selected for each group by a computer.
- Receive treatment have treatment
- Requires needs
- Scheduled to undergo due to have
- Signalling ways that cells communicate with each other
- Sufficient enough
- Suspicious abnormal
- Tablet form tablets
- The patient 'People with cancer'
- Thereafter after that
- The reason why this is this is because
- Vast majority of most
- What is the incidence of How common is
- Whilst while
- With reference to about
- With regard to about

Appendix 3: Examples of good plain language summaries

Example 1

Screening programs for breast, bowel and cervical cancers use age and gender to identify people most at risk. However several other risk factors, such as ethnicity, genetics, family history and lifestyle also contribute to cancer risk.

We will develop a new screening program for cancer using lifestyle, genetics and family history data to identify individuals at high risk. This will enable screening to be targeted at those with the greatest chance of getting cancer which will lead to more people having their cancer diagnosed earlier. This in turn will lead to better treatment and outcomes for people with cancer and lower healthcare costs. People who are free of disease and with a low risk of cancer will be spared the inconvenience and harms of screening.

Example 2

Colorectal (bowel) cancer is the second most common cancer and a major cause of death in Australia, accounting for almost 10% of all Australian cancer deaths. With an estimated 15,840 new cases being diagnosed last year alone, better prevention strategies are vital.

Colorectal cancer usually develops from polyps; fleshy growths that develop on the lining of the bowel due to abnormal cell growth. Finding these polyps and removing them can prevent people from developing bowel cancer.

A virtual colonoscopy is a method of detecting bowel polyps using an imaging technique called computed tomography (CT). CT is less invasive than the traditional optical colonoscopy. However, it exposes the patient to potentially harmful radiation.

We will determine the minimum dose of radiation required for the safest and most accurate detection of polyps by CT virtual colonoscopy, which will lead to a more effective way of detecting bowel polyps and preventing colorectal cancer.

Example 3

In this research project we will examine the association between passive smoking and cancers of the kidney and bladder. The links between smoking and these cancers has been previously documented and researched, but the effect of passive smoking has not.

We will conduct an examination (systematic review) of the published literature and other available research that investigates the link between passive smoking and kidney and bladder cancer. We will use a technique called 'meta-analysis' to combine the results of the studies we find to determine if passive smoking is associated with an increased risk of these cancers.

Example 4

People diagnosed with upper gastro-intestinal cancers (cancers of the oesophagus, stomach, liver, gallbladder and pancreas) have poor outcomes. Few have surgery because their disease is too advanced at diagnosis. For those that do, surgery can be complex.

When this surgery is performed in specialist units patient outcomes are better. Therefore, private and public health providers in WA have agreed that certain surgical procedures will only take place at major hospitals with specialised services. For changes like this to be effective, they need to be supported by consumers, clinicians, managers and government.

In this project we will determine whether these changes to surgical service delivery for upper gastro-intestinal surgery for cancer have been supported and have had a positive impact on outcomes for patients. We also aim to highlight areas where services can be improved.

Example 5

A common feature of cancer is the growth of blood vessels inside the developing tumour. Tumours need blood vessels to provide oxygen and nutrients for the cancer to grow.

Two types of cells in our body, macrophages and neutrophils, have been shown to help in the development of blood vessels. Macrophages and neutrophils are part of our immune system, which is the body's mechanism for fighting disease. Both cell types work differently and their functions may be altered by different stimuli, meaning that they may be excellent targets for cancer therapies.

In this project we will study how macrophages and neutrophils work in mice treated with different potential anti-cancer agents, to see if it is possible to normalise or reduce blood vessel growth, thereby slowing the growth of tumours.

Example 6

CDKN2A is a protein that controls cell growth. If cells stop making CDNK2A, it leads to uncontrolled growth and cancer development.

The production of CDKN2A is controlled by the CDKN2A gene. We know from previous research that the CDKN2A gene can be deleted in a type of immature liver cell called a liver progenitor cell or LPC. We think this transforms LPCs into liver cancer stem cells, an immature type of liver cell from which liver cancer is known to develop. In this project we aim to establish if this is the case.