Plain Language Summaries
A Tool for Scientific Communication & Inclusivity
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Overview

- What are Plain Language Summaries
- Why are they important?
- What can rhetorical analysis teach us about PLS?
- What tools, tips, and resources related to PLSs can we add to our writer toolboxes?
Comparing the writing skills of autistic and nonautistic university students: A collaboration with autistic university students

Kristen Gillespie-Lynch¹, Emily Hotez¹, Matthew Zajic²,³, Ariana Riccio¹, Danielle DeNigris¹,⁴, Bella Kofner¹, Dennis Bublitz¹, Naomi Gaggi¹ and Kavi Luca¹
The writing skills of autistic university students have received very little empirical attention. Previous research has suggested that autistic people may struggle with writing, in part, due to challenges with Theory of Mind. However, other research indicates that Theory of Mind difficulties are far from universal in autism, varying across developmental and social contexts. Through a participatory research approach, autistic university students contributed to the current study examining the writing strengths and challenges of autistic \((n=25)\) and nonautistic \((n=25)\) university students. Autistic participants demonstrated more advanced writing skills, more perfectionistic attitudes about writing, and heightened nonverbal intelligence relative to nonautistic students. Autistic students did not exhibit reduced Theory of Mind skills. Although heightened nonverbal intelligence and being autistic were both initially predictive of writing quality, autism was no longer associated with writing quality after accounting for nonverbal intelligence. Findings suggest that autistic university students may often have enhanced cognitive and writing skills but may face challenges overcoming perfectionism. This research highlights the value of participatory collaborations with autistic students for identifying strengths that can help autistic students succeed in college.
We do not know very much about the writing skills of autistic university students. Studies with autistic children and teenagers show that some autistic young people have difficulties writing. Other autistic people are talented writers. In fact, some autistic people would rather write than speak. Good writers often imagine other people’s points of view when writing. Autistic people sometimes have difficulties understanding others’ points of view. Yet, autistic people often work much harder to understand others’ points of view than non-autistic people do. We collaborated with autistic university student researchers to see if autistic university students are better or worse at writing than nonautistic students. Autistic university students in our study were better writers than nonautistic students. Autistic students in our study had higher nonverbal intelligence than nonautistic students. Autistic students also put themselves under more pressure to write perfectly than nonautistic students did. Autistic students did not show any difficulties understanding other minds. This study shows that some autistic university students have stronger writing skills and higher intelligence than nonautistic university students. Yet, autistic students may be too hard on themselves about their writing. Fun activities that help students explore their ideas without pressure (like theater games) may help autistic students be less hard on their writing. Teachers can help autistic students express themselves through writing by encouraging them to write about their interests, by giving them enough time to write, and by letting them write using computers if they want to. This study shows that collaborations with autistic people can help us understand strengths that can help autistic people succeed.
What is a Plain Language Summary (PLS)?

accessible, short, peer-reviewed summaries of scholarly journal articles written in non-technical language.
Types of PLS

- Text-based
- Infographic-based
- Full-length standalone

*Multi-media PLS including animation, video, and audio are becoming more common.
Rhetorical analysis offers a flexible framework for developing effective PLS.
Why are PLS important?

- Accessibility
- Transparency
- Engagement & empowerment
- Knowledge translation
Rhetorical Situation

Rationale, Scope, & Intended Audience
Potential Audiences of PLS

- Healthcare professionals;
- Patients
- Patient advocates and caregivers;
- Policymakers;
- People involved in interdisciplinary research, browsing articles on the website, or new to the field; and
- Journalists looking for interesting new research to feature.
Audience Considerations

- What is common knowledge you share?
- What will you need to define and unpack?
- What do readers care about or expect from the text?
- How is your research relevant to them?
- What information may they need about the broader context of your research?
Strategy

Ask someone from outside your scientific discipline to read your PLS and explain your study back to you.
Because “good writing” is context-dependent, learning to be an effective writer is a life-long pursuit. Laupus Library’s Professional Writing Consultant offers one-on-one or small group consultations for faculty to share their works-in-progress, receive feedback on specific aspects of texts, and learn new strategies for improving effectiveness in processes and products.

While working with faculty writers, Dr. Kerri Flinchbaugh brings a rhetorical lens, curious mind, and myriad of writing resources to provide scaffolded writing support and make each consultation an individualized experience.

To schedule an online or face-to-face appointment, contact Kerri at flinchbaughk@ecu.edu.

ADA Accommodation 252-737-1018 (voice/TTY)
Can your audience...

• Find what they need,
• Understand what they find the first time they read it, and
• Use what they find to meet their needs?
Context of PLS for Writers

- Required for some journal article submissions, grant applications, and project reports;
- Typically peer reviewed as part of manuscript submission package; and
- Expands reach of work.
Topic of PLS

- What is the context?
- What is new?
- What is the impact?
Voice of PLS

- Use active voice, rather than passive;
- Craft shorter sentences and paragraphs;
- Convey same information as Abstract;
- Revise jargon and STEM-specific language; and
- Write at a high school reading level.
Check out a reading scale.

- The Flesch Reading Ease and Flesch–Kincaid Grade Level formulas are embedded into Microsoft Word.
- To activate these tests, under options for spelling and grammar, check the box that says "Show readability statistics." Afterward, every time you run spellcheck on your document, readability scores will pop up.

Other readability scales include the Fry Readability Test 3, SMOG (Simplified Measure of Gobbledygook test), and Lexile Framework for Reading.
Text-Based PLS: Summarized

- Provide context
- Craft reader-centered organization
- Use active voice, not passive

- Compose shorter sentences and paragraphs
- Chose common, everyday words
- Make layout easy to follow
Examples: Case Studies

Plain Language Summary of Publication

Long term survival, effectiveness, and safety of treatment in patients with high-risk metastatic castration-sensitive prostate cancer: a plain language summary of the study

A Study Conducted to Check if is Safe and Works Well in Patients with Generalized Myasthenia Gravis: A Plain Language Summary of Study

How to say?

Prednisone: Pred-nuh-zone
Androgen: An-druh-jun
Prostate cancer: PROS-tayt KAN-ser

Enzymes are types of protein which help speed up the rate of a specific chemical reaction in the cell.

Neurotransmitters are body’s chemical messengers that transmit signals from nerve cells to muscles, or between different nerve cells.

Hormones are chemicals synthesized in the body that act as messengers for normal physiological actions.

Serotonin 5-HT2A receptors are essential for a large number of physiological functions in the central nervous system including regulation of dopamine.
Example: Study Design

What happened to the participants in this study?

Figure 2. How was the study conducted?

Screening phase
- 1036 participants already taking [oral, injectable] risperidone or oral antipsychotics screened

Open-label phase
- 1 to 4 months
- Participants previously on:
  - Oral antipsychotics
  - Injectable risperidone
- Initiated on [oral, injectable] risperidone

Transition phase
- Received [oral, injectable] risperidone

Maintenance phase
- 1 to 3 months
- Participants previously on:
  - Low dose
- Received [oral, injectable] risperidone

DB phase 12 months
- 702 participants entered DB phase
- 334 participants excluded

478 patients [700-1000 mg eq]
- 1 M
- 3 M
- 6 M
- 12 M

Placebo

224 patients [350-525 mg eq]
- 1 M
- 3 M
- 6 M
- 12 M

Placebo
Example: Results

### Extent of Disease

Advanced prostate cancer may spread to other parts of the body.

<table>
<thead>
<tr>
<th>Extent of Disease*</th>
<th>Bone (n=597)</th>
<th>Liver (n=597)</th>
<th>Lungs (n=597)</th>
<th>Lymph nodes (n=597)</th>
<th>Prostate mass (n=597)</th>
<th>Viscera (n=597)</th>
<th>Soft tissue (n=597)</th>
<th>Other (n=597)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone</td>
<td>580 (97%)</td>
<td>32 (5%)</td>
<td>73 (12%)</td>
<td>283 (47%)</td>
<td>151 (25%)</td>
<td>18 (3%)</td>
<td>9 (2%)</td>
<td>2 (&lt;1%)</td>
</tr>
<tr>
<td>Liver</td>
<td>585 (98%)</td>
<td>30 (5%)</td>
<td>72 (12%)</td>
<td>287 (48%)</td>
<td>154 (26%)</td>
<td>13 (2%)</td>
<td>15 (3%)</td>
<td>0</td>
</tr>
</tbody>
</table>

*Note: ADT represents androgen deprivation therapy.
Joel Bervell
- Yale Alum
- Medical Student
- Passionate about diversifying the field of medicine and understanding the biases that impact medicine

Dr. Ben Rein
- Stanford University
- Neuroscientist & Science Communicator
- Summarizes recent publications from neuroscience in plain language in under a minute
Thank you!

Kerri Bright Flinchbaugh, PhD
Laupus Library's Professional Writing Consultant
Assistant Director of the University Writing Program
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Why Plain Language Summaries?

Over the past 5 years, I’ve witnessed and admired a unified push towards increased transparency and disclosure for the general public. Patient-forward transparency not only builds and maintains public trust in clinical research, but also helps us all make informed healthcare decisions. I hope to see more and more open access and PLS initiatives in the near future!

Sudipta Chakraborty
Plain Language Summaries/Clinical Trial Transparency Manager, PRA Health Sciences
www.plainlanguagesummaries.com

Why Plain Language Summaries?

Information is being democratized and medical/scientific information is no exception. We need to ensure that people living with health conditions have access to the latest research in a way that it is understandable and meaningful so that everyone is able to better understand their disease and treatment pathways, in an age where shared-decision making is increasingly widespread and important. PLS will be crucial for this!

Trishna Bharadia
Owner, The Spark Global; Patient Advocate
www.plainlanguagesummaries.com

Why Plain Language Summaries?

Knowledge cannot be elitist – it needs to be accessible and understandable for all, leading to informed medical health choices and an improved quality of life.

Sheila Khawaja
Patient Engagement Consultant, Ripple Effect Communications; Rare Disease Patient Advocate
www.plainlanguagesummaries.com

Why Plain Language Summaries?

Plain Language Summaries are critical to helping the public understand the results of scientific/health research and clinical trials. ... PLS give people a necessary opportunity to read, understand, and learn about health and science topics germane to their lives. In addition, I believe that one reason many Americans don’t believe science is because scientific information is far too often written for experts, not for the public. PLS solve these problems by providing easy to understand information while, at the same time, building public trust.

Deborah S Bosley
Founder and Principal, The Plain Language Group, LLC
www.plainlanguagesummaries.com
Additional Examples of PLSs

- How Well the Single-Dose Janssen Vaccine Works
- Antifungal Drugs Work Together to Treat Germs Causing Fungal Infections
- The Effects of Iclepertin on Cognition in Patients with Schizophrenia
- Is the Sodium in Sodium Oxybate a Risk for Heart Health?
Additional Resources

- **Plain Language Summaries (PLS) of Peer-Reviewed Publications and Conference Presentations: A Practical ‘How-To’ Guide for Multi-Stakeholder Co-Creation**
  - This How-To guide is part of a series of PFMD How-To guides that have been co-created in a multi-stakeholder environment built with the Patient Engagement Quality Guidance as a starting point. All How-To’s are connected and provide a full set of instructions on how to involve patients across the research, development, and delivery of medicines.

- **Center for Plain Language**
  - The Center for Plain Language is a non-profit organization that helps government agencies and businesses write clearly. The website contains a plain language checklist, book recommendations, and before and after examples from various organizations.

- **Clear Communication - National Institutes of Health**
  - The NIH Office of Communications and Public Liaison (OCPL) has established the NIH “Clear Communication” initiative.

- **Plain Language Training at NIH**
  - The National Institutes of Health’s webpage provides links to online trainings.

- **Going Public: Writing About Research in Everyday Language**
  - This brief describes approaches that writers can use to make impact research more accessible to policy audiences.

- **Plain Language – Centers for Disease Control and Prevention (CDC)**
  - The Centers for Disease Control and Prevention identifies plain language resources including promotional materials on highlighting main messages and eliminating jargon and unnecessary details.
Thinking Through Your PLS

- Who is your intended audience? What common knowledge do you [not] share with them?
- What scientific terms or jargon relating to your study might need to be explained? What was the research question (in the larger context of your field)?
- What did your study find?
- Why does it matter (e.g. what’s the impact on society)?
- What’s the take-home message (e.g. what do you want people to most remember)?
One Way to Organize

- **Topic Overview** (1-3 sentences) – What does a non-specialist reader need to know about the topic to understand your paper? Explain the broad scientific topic to provide context for your study.
- **Paper Overview** (1-3 sentences) – What did you set out to investigate? Give a brief overview of what you set out to do in the research and how you went about it.
- **Findings Summary** (1-3 sentences) – What was the most significant result or conclusion in your paper? Describe your overall findings but don’t get caught up in explaining technical details.
- **Key Takeaways** (1-2 sentences) – Why should a reader care about your findings? Explain the scientific importance or societal relevance of your study.
Images & Examples from
Salgo Merin & Shweta Pitre
Unlocking Clarity: Plain Language Summaries
SIRO Clinpharm
Recorded 29 November 2023
https://www.youtube.com/watch?v=M_qO9jU_o98&t=2140s
MedCommons Networking webinar