

Posttraumatic Growth in People Living With Aphasia

An Experience in Stakeholder-Engaged Research

Tami U. Brancamp

The purpose of this original essay is to describe the process of developing a stakeholder-engaged research (SER) team with people who have aphasia. The SER process is described through the lens of posttraumatic growth and depreciation in aphasia. This article describes the process of modifying the Posttraumatic Growth and Depreciation Inventory (PTGI-42; Baker et al., 2008; Cann et al., 2010) with a multistakeholder research team so that individuals with aphasia may have a greater opportunity to be included in posttraumatic growth stroke outcome research. Posttraumatic growth is the positive psychological change that can be experienced as a result of the struggle with highly challenging life situations (Calhoun & Tedeschi, 2001) whereas posttraumatic depreciation is the inverse of growth, the negative aspects. To understand posttraumatic growth and depreciation in people living with aphasia, it is important that they be included in the research. To do so, we need to include people with aphasia in the research process and provide measurement tools that are aphasia friendly and accessible so that people with aphasia can participate in research and have their voices heard. This article describes the process, benefits, and challenges of stakeholder-engaged research. **Key words:** *aphasia, posttraumatic depreciation, posttraumatic growth, stakeholder-engaged research*

RESearch is often completed without collaboration with the group being researched. This can result in research outcomes that are less meaningful and relevant to all stakeholders, especially those

living with the condition being researched. Stakeholder-engaged research (SER) is the inclusion of stakeholders into the research process as active members in the planning and execution of the project. Stakeholders can be defined as any individuals, groups, or organizations that can affect, or can be affected by, another individual group, or organization (Friedman & Miles, 2002). In health care and implementation science, stakeholders may include patients, family members, clinicians, administrators, community-based leaders, and policy makers (Deverka et al., 2012). Stakeholder-engaged research results in an increase in research relevance, higher rigor, minimized logistical issues, increased collaboration, and more empowerment to both researchers and stakeholders (Ahmed & Palermo, 2010).

Author Affiliations: *Department of Speech Pathology & Audiology, University of Nevada, Reno School of Medicine.*

This work has been funded, in part, through a University of Nevada, Reno School of Medicine, Faculty Development Funding Award and was partially supported by a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (17449-NSU).

The author and planners have disclosed no potential relevant financial relationships or otherwise. Author disclosures can be found at <http://links.lww.com/TLD/A104>.

Corresponding Author: *Tami U. Brancamp, PhD, Department of Speech Pathology & Audiology, University of Nevada, Reno School of Medicine, MS 0152, 1664 N Virginia St, Reno, NV 89557 (tbrancamp@med.unr.edu).*

DOI: 10.1097/TLD.0000000000000306

SER IN APHASIA

The Patient-Centered Outcomes Research Institute's (PCORI) model of SER advocates

engagement in research, which includes involvement of patients, caregivers, clinicians, researchers, and others in the health care community in every aspect of the project (Patient-Centered Outcomes Research Institute, 2022). This approach takes consumers or individuals affected by a disease or condition out of the patient role where research is done to them and invites them to actively engage in the research process from inception of an idea all the way through to the conclusion of the research project to dissemination of results.

Stakeholder-engaged research is growing in importance within the United States as well as internationally. Outside of the United States, SER goes by other names including public and patient involvement, consumer involvement, codesign, and coproduction (Locock & Boaz, 2019; McMenamin et al., 2022).

The inclusion of people with aphasia (PWA) in post-stroke research is growing in importance, as well. Cruice et al. (2022) used the coproduction process (e.g., SER) in the development of the Linguistic Underpinnings of Narrative in Aphasia (LUNA) research project. Development of research questionnaires and outcome measures designed to be accessible to those with aphasia were code-signed through a SER process (Kearns et al., 2019; Shiggins et al., 2022a). Stakeholders worked in collaboration with researchers to design, implement, and measure outcomes of a yoga practice with PWA (Bislick et al., 2022).

This original essay describes the SER process as viewed through the lens of post-traumatic growth (PTG) and posttraumatic depreciation (PTD) in aphasia. This article will briefly discuss PTG and PTD and their application in stroke outcome research and specifically what we know about PTG and PTD in PWA. This project started in 2018 when there was a lack of available guidelines on how to engage in SER with PWA, resulting in a project that morphed over time as we learned what was necessary to complete the project in an inclusive manner. The author will share how each group within the PTG and depreciation in aphasia stakeholder-

engaged research teams (PTG-Aphasia SER) was formed and their responsibilities and contributions to the project. This includes the recruitment and development of an aphasia advisory team (AAT) with the goal to evaluate the accessibility of the Posttraumatic Growth and Depreciation Inventory (PTGI-42; Baker et al., 2008; Cann et al., 2010) and to modify it, if necessary, to make the inventory more accessible to PWA. Then I will describe the process of expanding the AAT into a larger multistakeholder research team and why it was necessary to do so.

PTG AND DEPRECIATION

Tedeschi and Calhoun (1996) define PTG as positive psychological changes experienced as a result of the struggle with a traumatic or highly challenging life circumstances (Tedeschi et al., 2018). Posttraumatic growth focuses on longer-term changes that come about after personal reflection where the individual has time to develop new ways of thinking, feeling, and behaving because the events that have been experienced do not permit a return to baseline functioning. In PTG, change is transformative and involves positive changes in cognition and emotional life that are likely to have behavioral implications (Calhoun & Tedeschi, 2006). Posttraumatic growth differs from personal development, maturity, and/or growth in that PTG occurs because of a struggle with the aftermath of a major life crisis. The struggle that leads to PTG is not usually at first a challenge to grow or change but rather to survive or cope. But not all change in the post-event life is perceived as positive growth, some can be negatively oriented. Posttraumatic depreciation is considered the inverse of PTG and refers to the negative changes one might experience in the phenomenon of posttraumatic transformation (Baker et al., 2008; Cann et al., 2010).

PTG IN STROKE RESEARCH

Stroke is a leading cause of serious long-term disability (Centers for Disease Control

and Prevention, 2022) and can be considered a traumatic event in that it is unexpected, uncontrollable, and is potentially life threatening often challenging an individual's view of themselves and the world around them (Kelly et al., 2018). Numerous studies that have focused on health-related quality of life (HRQL) predictors in stroke survivors identified depression/emotional distress and functional status/physical disability as the most consistent HRQL predictors in stroke (Hilari et al., 2012). Stroke survivors with aphasia experience even greater disability than stroke survivors with no aphasia (Flowers et al., 2016). Having aphasia can be isolating due to the loss of social and vocational networks. With that can come isolation, boredom, loss of personhood, lack of control, frustration, and depression (Nätterlund, 2010; Parr, 2007; Vickers, 2010).

Unfortunately, not all stroke outcome research includes PWA. Research that has included PWA shows that aphasia has a profound effect on people's lives, both the stroke survivor with aphasia and the cosurvivors (Simmons-Mackie, 2018). Emotional distress, aphasia severity, communication and activity limitation, medical problems, and social networks and support affect HRQL in PWA poststroke (Hilari et al., 2012). Posttraumatic growth is one way to examine poststroke life. Unfortunately for stroke survivors with aphasia, the majority of published studies on PTG in stroke survivors have excluded all but a few people with language and/or cognitive impairments (Kelly, 2015; Kuenemund et al., 2016; Gangstad et al., 2009; Gillen, 2005; Peng & Wan, 2018). With an estimate of 6,500,000–7,500,000 people in the United States living with stroke and an estimate of one-third of stroke survivors having aphasia, there are many voices that are not being included in stroke outcome research (Simmons-Mackie, 2018).

Posttraumatic growth has been studied in various realms including but not limited to war and military engagements, assault, terrorist events, spinal cord injury, amputation, cancer, cardiac disease, traumatic brain injury, and stroke (Tedeschi et al., 2018). As

PWA are primarily excluded from research on PTG in stroke, there is little information on how PWA may experience the transformation necessary for PTG. In the poststroke life, the person with aphasia must grapple with their changed identity in order to reconcile who they used to be with who they are today (Mackay, 2003; Shadden & Agen, 2004; Shadden & Koski, 2007). Sherratt and Worrall (2019) described instances of PTG as reflected in personal experiences of PWA. Their review of personal narrative reports revealed multiple examples in which PWA experienced positive aspects to recovery that closely relate to the domains of PTG. To understand the unique contribution of PTG and depreciation with PWA, it is important that they be included in the research and that researchers reduce barriers to participation in research by creating measurement tools that are accessible and comprehensible for them (Charalambous et al., 2022).

ASSESSING PTG AND DEPRECIATION

Most often, PTG is assessed using the 21-item Posttraumatic Growth Inventory (PTGI-21; Tedeschi & Calhoun, 1996). This inventory consists of five factors or domains: personal strength, relating to others, new possibilities, spiritual change, and appreciation of life. Changes in these areas are measured as the experience of a highly stressful or traumatic life event. The PTGI-21 has been criticized as only measuring positive changes as people do experience both positive and negative changes in life after a traumatic event (Tedeschi et al., 2018). Research that has examined both positive and negative changes simultaneously suggests that predictors of PTG are not the same as predictors of PTSD (Shakespeare-Finch & Lurie-Beck, 2014). To remedy the fact that negatively oriented changes can occur and should be measured, the 42-item Paired Format Posttraumatic Growth Inventory (PTGI-42) was developed. The PTGI-42 examines both PTG and PTSD by having respondents report positive change (e.g., the original PTGI-21) and

21 matched, negatively worded paired items (Baker et al., 2008; Cann et al., 2010).

PTG AND APHASIA

Around the same time, the PTG-Aphasia SER began exploring PTG in aphasia in the United States. Sherratt and Worrall (2020) were examining PTG in 13 PWA during their first year poststroke in Australia. Neither team realized that the other was evaluating the inventory to determine whether it needed to be modified to be more accessible to PWA. Sherratt modified the PTGI-21 (Tedeschi & Calhoun, 1996) by changing the response layout and color and adding a carrier phrase, “As a result of your aphasia would you say” These modifications were completed by the researcher and did not engage an SER approach. This study examined PTG but not PTD. Results revealed that participant’s PTGI scores ranged from 10 to 91 (maximum score being 105) with no significant differences in the mean total scores, nor across the PTGI domains over the four time periods assessed. Domains of new possibilities and spiritual and existential change scored relatively low at all time periods. Whereas relating to others, appreciation of life and personal strength consistently showed most growth at each time period. Results indicate that some of the participants started the journey of redefining themselves as they navigated their new identity as a person living with aphasia and were able to report on their self-perception of PTG. Sherratt and Worrall (2019, 2020) provided the initial published research that illustrated that PWA are capable of experiencing PTG after stroke, which provides greater evidence that PWA should be included in PTG in stroke outcome research. Our team believed that both PTG and PTD should be explored in PWA.

PTG IN APHASIA STAKEHOLDER-ENGAGED RESEARCH TEAM (PTG-APHASIA SER)

The PTG-Aphasia SER included three distinct groups: consumer members of the AAT,

expert members of the AAT, and researchers, clinicians, and consumers of the BRIDGE SER team. This author was project lead and a member of all three groups. See Figure 1.

AAT—consumer and expert members

Recruitment to the AAT was initiated on August 24, 2018, with the Aphasia Center of Nevada, located at the University of Nevada, Reno. An invitation was posted on the group’s private Facebook page. The post asked members whether they wanted their voices to be heard? Were they interested in advising, guiding, and talking about PTG in aphasia? The same recruitment was brought to the bimonthly conversation group meeting the same month. Those who expressed interest were invited to the initial meeting on September 4, 2018. The first meeting discussed PTG and depreciation in stroke survivors and that the majority of that research did not include PWA or did so minimally. We discussed the aims of the project and what team members could expect in terms of time involvement and that their involvement would be fully voluntary and without compensation as this project was completed without any grant funding. Six individuals with aphasia and their cosurvivors (care partners) initially volunteered to participate. One husband and wife team decided that this type of research was not of interest and chose not to continue. The remaining five couples had been living with aphasia between 3 and 10 years. All members with aphasia are classified as having nonfluent aphasia with the majority having moderate aphasia, one with moderate-severe aphasia. Decisions on additional team members were guided by the goals of the project and additional professional knowledge needed for a project of this scope. Expert members were recruited on the basis of their expertise in aphasia, language and literacy, and assessment development. Consumer members and expert members were informed that the purpose of the AAT would be to collaborate on a research project examining PTG and depreciation in aphasia. We would examine the existing PTGI-42 and determine whether it

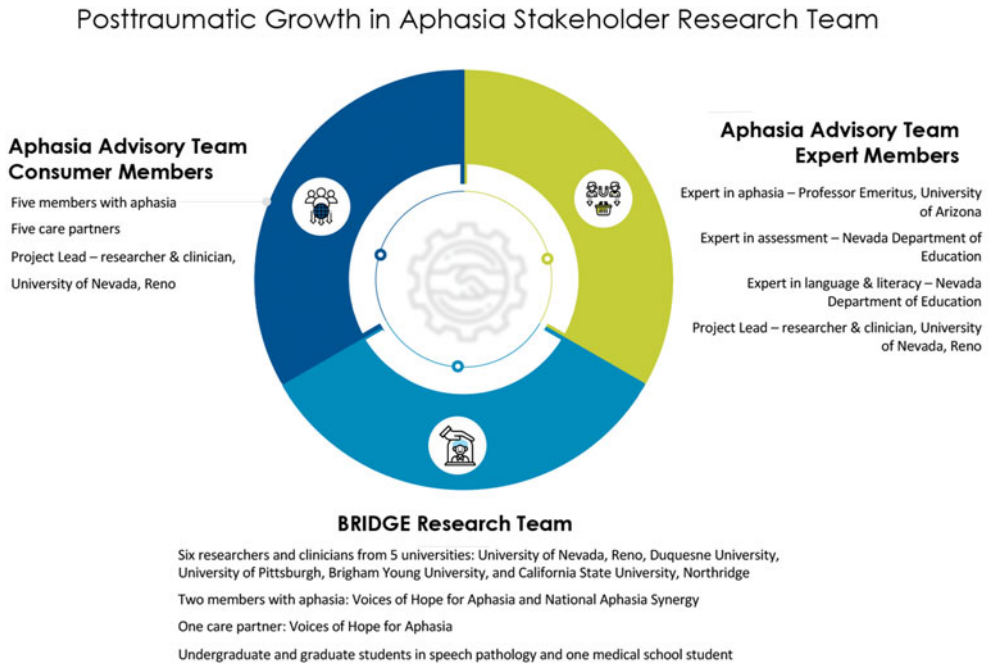


Figure 1. Posttraumatic growth in aphasia stakeholder research team. This figure is available in color online (www.topicsinlanguage disorders.com).

was accessible and appropriate for PWA. If, in their opinion, it was not, we would complete a systematic modification of the PTGI-42 to make it accessible so that PWA could be included in PTG and PTD research. The AAT Consumer members and the project lead met three times for approximately 1.5–2 hr per meeting between September 6, 2018, and January 18, 2019. The project lead met with the AAT expert members five times between October 18, 2018, and April 9, 2019.

Meetings with the AAT expert members were intermittent and based on the phase of the project. Over five meetings, project lead and expert members modified the original statements that were deemed to be syntactically complex and potentially confusing to PWA, reviewed the positive and negative word pairs, corrected grammar, generated practice items and modified instructions, and assessed the readability of the original and modified measures. All changes and recommendations were reviewed with the AAT consumer group and they participated in beta testing each revision. Their comments and

recommendations were taken back to the AAT expert group for any necessary modifications.

In 2018, this author was unaware of Sherratt and Worral's (2020) modifications to the PTGI-21, so we could not build upon their work and, therefore, started from the beginning. During the first meeting of the AAT consumer group, this author shared the historical perspective of PTG and PTD. Research on PTG and PTD with stroke survivors was summarized and we discussed the exclusion of PWA from the majority of those studies. Researchers acknowledge that there exist barriers to including individuals with language disorders in research including the consent process, assumption of lack of capacity versus presumption of capacity, data collection processes, and highly language-dominant outcome measurement tools (Shiggins et al., 2022b). Although a researcher may understand the reasons PWA may be excluded from studies due to language difficulties, the AAT consumer members expressed discontent and disappointment that PWA were not

included in the research about them. This brought all of us to a shared perspective and the AAT planned our approach to changing this paradigm through the path of PTG and depreciation in aphasia. The first task was to have the PWA members complete the original Posttraumatic Growth & Depreciation Inventory (PTGI-42; Baker et al., 2008; Cann et al., 2010). Initially, PWA attempted to complete the inventory on their own. It was quickly discovered that members were unable to independently read the inventory statements, refer to the rating scale, and respond. Members shared that they could read a few words but not the entire inventory. One member shared that she could type the words into her smartphone and have them read aloud to her, but that would be very time-consuming. It was determined that the project lead would read each statement aloud to all consumer members. Each member then answered the statements based on his or her own beliefs and self-perception. After the PTGI-42 was completed, each member shared his or her individual perspectives on completing the inventory. Collectively, the PWA members determined that the inventory was difficult to complete as it was originally written and in the presented format. They did not consider it an accessible and aphasia-friendly instrument. An aphasia-friendly format is one that includes abundant white space, large (14 pt) and standard font, simplified syntax, and vocabulary with relevant pictures or icons (Rose et al., 2003). The AAT consumer members identified three primary areas that needed to be revised: format of the inventory, grammatical complexity, and rating scale/response form.

Orthographic format

The inventory was originally designed for adults who do not have a language or literacy impairment. It is in a 10 or 11 font size with paired statements spaced close together. Although the rating scale is printed on each page, it is orthographic only. Consumer AAT members reported that the format was diffi-

cult for them to process due to their aphasia and alexia.

Grammatical complexity of statements

A few members shared that although they understood when the statement was read to them, it was difficult to recall the orthographic Likert scale in order to respond (see Table 1). They expressed that the inventory had too many words and no picture support. Consumer AAT members suggested that picture support of key words or expressions would be helpful and should be put in the modified version. The AAT discussed the imageability of a few inventory statements as this author did not know how to select a picture that would represent statements such as (1a) "I changed my priorities about what is important in life" or (2a) "I have a greater appreciation for the value of my own life." The intent of the modification was to maintain the original meaning of each statement as close as possible without influencing a participant's personal perspective. Through discussion, the consumer AAT agreed that finding ready-made pictures for this inventory was not realistic, but we could improve the rating scale to be more aphasia-friendly.

The consumer AAT discussed whether we should use the PTGI-21 where it looks at

Table 1. Original PTGI-42 (Baker et al., 2008; Cann et al., 2010) orthographic response scale. Used with permission.

0 = I did not experience this change as a result of my crisis.
1 = I experienced this change to a very small degree as a result of my crisis.
2 = I experienced this change to a small degree as a result of my crisis.
3 = I experienced this change to a moderate degree as a result of my crisis.
4 = I experienced this change to a great degree as a result of my crisis.
5 = I experienced this change to a very great degree as a result of my crisis.

Note. PTGI = Posttraumatic Growth and Depreciation Inventory.

only positively oriented change or whether we should look at the negatively oriented changes (PTGI-42) as well. The consumer AAT was in agreement that 42 questions created a fairly long assessment, but to date, nobody had asked these questions of PWA. We agreed to include both the growth and depreciation sections, but some of the statements needed modification to be better understood by a person with a language impairment. Cann et al. (2010) explained that the paired comparisons permit respondents to think about their postevent self more holistically—to consider growth and depreciation concurrently for each item. The consumer AAT members said that when they completed the inventory, they considered both the positive and the negative statements and that they felt that it was appropriate to continue the paired comparison format in our modified version thus keeping our modified version as close to the original as possible.

Rating scale/response form

The project lead brought multiple examples of aphasia-friendly assessments and inventories to support the consumer AAT's discussion of revising the response form/rating scales. The team reviewed the format of the Assessment for Living with Aphasia (ALA; Simmons-Mackie et al., 2014), the Stroke and Aphasia Quality of Life Scale (SAQOL-39; Hilari et al., 2003), the Modified Perceived Stress Scale (mPSS; Pompon et al., 2018), and the ASHA Quality of Communication Life Scale (QCL; Paul et al., 2004). Consumer AAT members liked the measurement tools that had a rating response for each question or on each page. They preferred a horizontal orientation to a vertical response format (e.g., QCL). Having pictures to represent positive and negative ends of the scale (e.g., the ALA) or having pictures of calendars with days and weeks marked to indicate frequency (e.g., mPSS) was well received. As a team, we discussed how to create a pictorial rating scale that would reflect the original PTGI-42 scale. This process required multiple trials and modifications to meet the recom-

mendations of the consumer and expert AAT members. Figure 2 and Table 1 reflect the pre- and postmodification rating scales.

The modified version of the PTGI-42 was renamed the Posttraumatic Growth and Depreciation Inventory—Aphasia (PTGI-Aphasia). Once the members of both the expert AAT and the consumer AAT were satisfied that all modifications to the inventory format and rating scale were complete, the PTGI-Aphasia was administered to the consumer AAT for comparison with the original PTGI-42. At the initial administration, the PTGI-42 required 30–40 min to complete where the project lead read each statement aloud, members responded to the original rating scale independently, frequently referring back to the original page describing the rating scale. The modified PTGI-Aphasia was completed within 10–20 min. Consumer AAT members said that they liked the paired format with both the positive and negative questions on the same page with a rating scale associated with each question. They liked the rating scale that had numbers and anchor descriptions for each point on the 5-point Likert scale. The AAT discussed creating the scale in color versus black and white or shades of gray and came to consensus that it would be easier to print or copy if the scale was presented in a graduated gray scale rather than color.

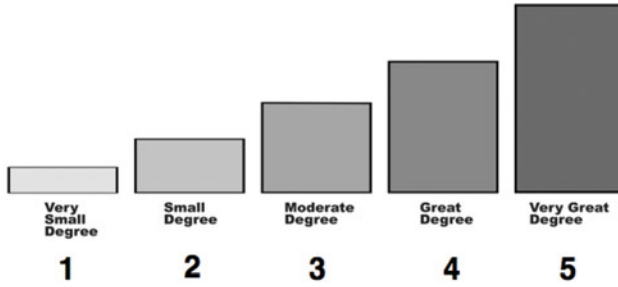
Grammar modifications

The consumer AAT members expressed confusion on a few of the PTG and PTD statements that were grammatically complex. At this point, the partially revised PTGI-Aphasia was sent over to the AAT members with expertise in aphasia, assessment, language, and literacy. This smaller group of four members was asked to apply their expertise to modify the grammar on some of the PTGI-42 statements. The group followed best practices guidelines for plain language (National Institutes of Health, 2022) and creating aphasia-friendly print materials. The team of experts reviewed all positive and negative pairs, examined the perceived

As a result of your aphasia,

1a) Have you changed what you consider important in life?

- No
- Yes
 - If yes, to what degree?



1b) Do you find it difficult to change what you consider important in life?

- No
- Yes
 - If yes, to what degree?

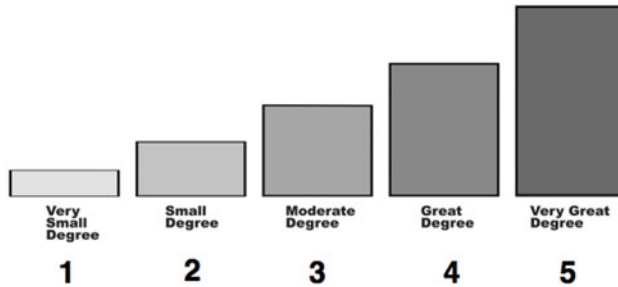


Figure 2. PTGI-Aphasia pictographic rating scale.

complexity of each statement, and discussed which statements should be modified to be more aphasia-friendly while maintaining the meaning of the original statement. The original PTGI-42 is formatted as statements where the participants respond to the degree of change they have experienced (Table 1), for example, item 4b “I have a diminished feeling of self-reliance,” item 10a “I know better that I can handle difficulties,” and item 14a “New opportunities are available which wouldn’t have been otherwise.” The smaller group of experts participated in three meetings to make grammar modifications. Modifications included simplified syntax for

some statements. For example, PTGI-42 item 1a “I changed my priorities about what is important in life” was changed to “Have you changed what you consider important in life?” The expert AAT members discussed working memory and aphasia (Salis et al., 2015) and decided to reduce the cognitive load on participants by presenting the inventory in the form of questions. By doing so, the participants would not need to perform the transformation of the statement into a question in order to respond. The question format is also consistent with other aphasia inventories such as the ALA (Simmons-Mackie et al., 2014), the SAQOL-39 (Hilari et al., 2003),

and the mPSS (Pompon et al., 2018). See Table 2.

Readability

Readability measures of the original PTGI-42 (Baker et al., 2008; Cann et al., 2010) and the PTGI-Aphasia were compared. Readability is influenced by word choice including syllable structure and word complexity as well as syntactic structure of sentences. Readability, content, and design elements impact participant’s ability to understand the presented information (Doak et al., 1996). The PTGI-Aphasia has a readability level of fourth grade to fifth grade, which is in the recommended range to promote health literacy (Doak et al., 1996), whereas the original PTGI-42 was fifth grade to sixth grade. Readability measures are based on a readability consensus based on eight readability formulas (Readability Formulas, 2022). Through the modification process, we reduced total number of words from 377 to 355 and reduced the average number of words per sentence from nine to eight. After the expert AAT members offered their modifications, the PTGI-Aphasia was brought back to the consumer AAT for review, comments, and approval. Once the PTGI-Aphasia was in its final form, it was time to explore the validity of this modified instrument. To do this well, our AAT needed to expand its membership.

PROJECT BRIDGE (BUILDING RESEARCH INITIATIVES BY DEVELOPING GROUP EFFORT) STAKEHOLDER-ENGAGED RESEARCH TEAM (BRIDGE SER)

The Project BRIDGE conference (2018) was a 2-day event that brought together stakeholders interested in aphasia research. The experience of Project BRIDGE was instrumental in creating the larger and more diverse SER team necessary to progress our understanding of PTG and depreciation in aphasia and to examine the validity of the modified instrument. During the Project BRIDGE conference, a group of participants interested in quality of life in aphasia joined the Posttraumatic Growth in Aphasia SER team. The membership changed during the first 3 months as some participants of Project BRIDGE chose to discontinue their involvement due to personal and professional schedules and life events. Additional aphasia researchers who did not attend Project BRIDGE were invited to join the BRIDGE SER team. For the last 2 years, BRIDGE SER team has consisted of researchers and clinicians from University of Nevada, Reno, Duquesne University, University of Pittsburgh, Brigham Young University, and California State University, Northridge. The BRIDGE SER members with aphasia and care partners are from Voices of Hope for Aphasia and National Aphasia Synergy. See Figure 1.

Table 2. Examples of original PTGI-42 statements with corresponding PTGI-Aphasia modifications

	PTGI-42 Original Statements (Baker et al., 2008; Cann et al., 2010)	PTGI-Aphasia—Examples of Modifications
4b	I have a diminished feeling of self-reliance.	As a result of your aphasia: Do you rely on yourself less?
10a	I know better that I can handle difficulties.	Are you able to handle life difficulties better?
14a	New opportunities are available which wouldn’t have been otherwise.	Are new opportunities available to you now?

Note. PTGI = Posttraumatic Growth and Depreciation Inventory.

Members of the AAT consumer and expert groups were invited to continue the project, but each expressed that they had contributed to the PTGI-Aphasia modifications and felt that is where they were best able to serve the PTG-Aphasia SER team. Allowing stakeholders to participate in the way they feel that they can best contribute to the entire project is in alignment with the tenants of SER (Patient-Centered Outcomes Research Institute, 2022). To work together as a cohesive team, the BRIDGE SER group needed to discuss each member's individual research and clinical philosophies, preferred roles and level of involvement, and come to consensus on the research aims. One of the great benefits of a SER team is the diversity of its membership. Team members come with personal and professional talents and gifts that serve the collective. As individuals, we can express where we feel we can best contribute to the team framework and research aims. Although the consumer and expert members of the AAT handed off a singular modified inventory with the intent to validate the PTGI-Aphasia, the larger BRIDGE SER team expanded the original scope of work. As the purpose of this original essay is to discuss the process of the PTG-Aphasia SER, the outputs of the BRIDGE SER research will be discussed in a different article.

To complete an SER project of this magnitude, quality and consistent communication was a necessity. The BRIDGE SER team met every 2 weeks for 2 years. Team meetings kept us on target with roles and actions each member agreed upon. Team members with aphasia served as internal reviewers for our aphasia-friendly consent forms prior to institutional review board submission. Other team members (person with aphasia and care partner) served as practice research participants. We were able to complete a trial run of the research protocol to determine whether the presentation was organized, testing materials were aphasia-friendly, and instructions made sense, and determine how much time a data collection session would need. Team mem-

bers provided feedback on the process and adjustments were implemented.

Once institutional review board approval was obtained, participant recruitment began. The intent of most research is to obtain a broad sample of people living with the condition being examined. To connect with a variety of PWA across the country, BRIDGE SER members reached out to professional relationships, aphasia centers, and social media groups. The BRIDGE SER team was in agreement that all recruitment materials would be aphasia-friendly so that PWA could understand the purpose of the research project. Two team members (one PWA, one researcher) created an aphasia-friendly video to accompany our print recruitment materials. The link was available to be shared in stroke and aphasia social media sites as well as via email to aphasia centers and groups. This resulted in invitations to present to various stakeholder groups (e.g., aphasia centers and virtual connections) where both a researcher and a person with aphasia discussed the research project and invited members to participate in the research.

SHARING THE RESEARCH WITH ALL STAKEHOLDERS

Research results are typically published in peer-reviewed journals that are often not easily accessible and available to consumers. The BRIDGE SER team has completed both the quantitative and qualitative arms of our project and those results will be shared in different articles. Next is dissemination where we will submit the research findings to peer-reviewed journals for publication as well as sharing with the general public, specifically with PWA. To disseminate research findings to the public, it is necessary to consider multiple methods of improved accessibility and readability. Our BRIDGE SER team is developing alternate summaries of our research (Dube & Lapane, 2014; Linte, 2009) following principles of plain language as outlined by the National Institutes of Health and aphasia-friendly printed education materials. There

is overlap in these two approaches to consumer health education including the use of simple words and short sentences. Aphasia-friendly materials will also use a larger and standard font, more white space, and relevant pictures (Rose et al., 2003; Rose et al., 2011). The National Institutes of Health advocates for review of materials by members of the intended audience, for example, individuals living with aphasia and cosurvivors/care partners, followed by review of feedback and making necessary revisions. As a next step, the BRIDGE SER will include the original consumer AAT members in a review of the alternate, aphasia-friendly summaries of the research outcomes in PTG and depreciation in aphasia. Members will provide feedback on the print and video education materials to determine whether they are consumer- and aphasia-friendly thus bringing this project full circle.

SER BENEFITS, CHALLENGES, AND RECOMMENDATIONS

We have learned a lot over the life span of this project. The BRIDGE SER team collaborated to create a list of benefits, challenges, and recommendations for SER based on our experience (Hinckley et al., 2021).

Benefits of SER

- People living with communication challenges are actively involved in the project. They are contributing in meaningful ways that are important to them.
- We communicate about complex issues in research but make it accessible to all team members. We keep learning and getting better at communication.
- We are persistent, resilient, and patient with each other.
- All team members are volunteers as nobody had grant funding, yet we continued to do the research that was meaningful to the group.
- We were able to continue this research during a global pandemic and we are

grateful to the technology and the zoom videoconference platform.

- In the words of a BRIDGE SER team member who has aphasia, “I like the whole shebang. The teams. I work[ed] at Apple project manager and I like teams. I miss the teams, but now is cool because the teams and the purpose. I like the analyzing questions.”

Challenges with SER

- Time is a challenge. Clinician members were not able to join in on the research meetings as they could not get release time from their employment to consistently participate.
- Taking time to learn about each member and discover which aspects of the research project each wanted to participate was time-consuming but valuable.
- Making all communication aphasia-friendly is challenging. We learned to reduce the use of acronyms. We made sure to pause more, allow time for all members to speak, and to ask clarifying questions to be sure that we all understood the message.
- Making assumptions that a person with aphasia would not be interested in analyzing the data. We learned to ask and not assume. Some team members wanted to be involved with the entire research project from start to finish. Others wanted to ensure that recruitment materials, testing materials, and consents were appropriate and effective for our research participants.
- BRIDGE SER team member who has aphasia summarized the challenges well. “The challenge is ... research is ... jargon or something, uh excuse me, I don’t understand ... and is slow!”

BRIDGE SER Team recommendations

- Be patient; it will take more time to complete. There is less time line control when working with a team and it is a process to learn how to work together.

- Ask rather than assume. Assumptions impact trust. Admit when we messed up. Do not assume the minutia of research is not of interest to team members.
- Schedule regular meetings. This holds us accountable to each other and the project as a whole.
- Involve students. We hope that SER informs students as they become researchers and clinicians.
- Bring together people who have a shared desire to participate in research *with* the people living with the condition. This results in researchers and stakeholders feeling more empowered to make meaningful contributions.
- Being part of a team is a good thing. Get involved. Make a difference.

CONCLUSION

The goal of this personal essay was to share the experience of engaging in a collaborative SER project where stakeholders were actively involved in reviewing and modifying the PTG and depreciation inventory (PTGI-42; Baker et al., 2008; Cann et al., 2010), creating a new rating scale, and planning and implementing a large research project. Through this stakeholder-engaged process, we were able to continue the conversation of PTG in aphasia and start the conversation on PTD in aphasia by implementing a

project dedicated to inclusion and equity. Stakeholders were invited to come together to work on a shared project. And by coming together, each member brought their own unique combination of gifts and talents. Each person came with a set of professional and personal attributes that contributed to the collective project, contributing in a way that was meaningful to them and within their own personal desired level of contribution and capabilities. The synergy of the group resulted in a project that was meaningful to all members, personally and professionally. It mattered that the voices of the people we serve were heard in research and in our society. It mattered that clinicians contributed to research and it mattered that researchers were able to come together with different and shared perspectives to create a project that will ultimately contribute knowledge to the professional literature and to our consumers. People with chronic stroke, with and without aphasia, are willing to be involved in SER, but researchers need to provide the necessary supports for communicative and other stroke-related needs and invite them to participate (Charalambous et al., 2022).

The process of SER is not necessarily quick, nor is it easy, but its benefits truly outweigh the challenges. As Maya Angelou is credited with saying, “Do the best you can until you know better. Then when you know better, do better.” In this author’s opinion, SER is a step toward doing better.

REFERENCES

- Ahmed, S. M., & Palermo, A. G. (2010). Community engagement in research: Frameworks for education and peer review. *American Journal of Public Health, 100*(8), 1380–1387. <https://doi.org/10.2105/AJPH.2009.178137>
- Baker, J. M., Kelly, C., Calhoun, L. G., Cann, A., & Tedeschi, R. G. (2008). An examination of post-traumatic growth and posttraumatic depreciation: Two exploratory studies. *Journal of Loss and Trauma, 13*(5), 450–465. <https://doi.org/10.1080/15325020802171367>
- Bislick, L., Dietz, A., Duncan, E. S., Garza, P., Gleason, R., Harley, D., Kersey, G., Kersey, T., Mamlekar, C., McCarthy, M. J., Noe, V., Rushlow, D., Rushlow, J. C., & Van Allen, S. (2022). Finding “Zen” in Aphasia: The benefits of yoga as described by key stakeholders. *American Journal of Speech Language Pathology, 31*, 133–147. <https://doi.org/10.23641/asha.17003464>
- Calhoun, L. G., & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss. In *Meaning reconstruction & the experience of loss* (pp. 157–172). American Psychological Association.
- Calhoun, L. G., & Tedeschi, R. G. (Eds.). (2006). *Handbook of posttraumatic growth: Research and practice*. Taylor & Francis Group.
- Cann, A., Calhoun, L. G., Tedeschi, R. G., & Solomon, D. T. (2010). Posttraumatic growth and depreciation

- as independent experiences and predictors of well-being. *Journal of Loss and Trauma*, 15(3), 151-166. <https://doi.org/10.1080/15325020903375826>
- Centers for Disease Control and Prevention. (2022). Stroke Facts. <https://www.cdc.gov/stroke/facts.htm>
- Charalambous, M., Kountouri, A., Phylactou, P., Triantafyllidou, I., Annoni, J., & Kambanaros, M. (2022). The views of people living with chronic stroke and aphasia on their potential involvement as research partners: A thematic analysis. *Research Involvement and Engagement*, 8(1), 48. <https://doi.org/10.1186/s40900-022-00379-1>
- Cruice, M., Auja, S., Bannister, J., Bottig, N., Boyle, M., Charles, N., Dhaliwal, V., Grobler, S., Hersh, D., Marshall, J., Morris, S., Pritchard, M., Scarth, L., Talbot, R., & Dipper, L. (2022). Creating a novel approach to discourse treatment through coproduction with people with aphasia and speech and language therapists. *Aphasiology*, 36(10), 1159-1181. <https://doi.org/10.1080/02687038.2021.1942775>
- Deverka, P. A., Lavalley, D. C., Desai, P. J., Esmail, L. C., Ramsey, S. D., Veenstra, D. L., & Tunis, S. R. (2012). Stakeholder participation in comparative effectiveness research: Defining a framework for effective engagement. *Journal of Comparative Effectiveness Research*, 1(2), 181-194. <https://doi.org/10.2217/cer.12.7>
- Doak, C. C., Doak, L. G., & Root, J. H. (1996). Teaching patients with low literacy skills. *American Journal of Nursing*, 96(12), 16M.
- Dubé, C. E., & Lapane, K. L. (2014). Lay abstracts and summaries: Writing advice for scientists. *Journal of Cancer Education*, 29(3), 577-579. doi:10.1007/s13187-013-0570-1
- Flowers, H. L., Skoretz, S. A., Silver, F. L., Rochon, E., Fang, J., Flamand-Roze, C., & Martino, R. (2016). Post-stroke aphasia frequency, recovery, and outcomes: A systematic review and meta-analysis. *Archives of Physical Medicine and Rehabilitation*, 97(12), 2188-2201. <https://doi.org/10.1016/j.apmr.2016.03.006>
- Friedman, A. L., & Miles, S. (2002). Developing stakeholder theory. *Journal of Management Studies*, 39(1), 1-21. <https://doi.org/10.1111/1467-6486.00280>
- Gangstad, B., Norman, P., & Barton, J. (2009). Cognitive processing and posttraumatic growth after stroke. *Rehabilitation Psychology*, 54(1), 69-75. <https://doi.org/10.1037/a0014639>
- Gillen, G. (2005). Positive consequences of surviving a stroke. *American Journal of Occupational Therapy*, 59(3), 346-350. <https://doi.org/10.5014/ajot.59.3.346>
- Hilari, K., Byng, S., Lamping, D. L., & Smith, S. C. (2003). Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39): Evaluation of acceptability, reliability, and validity. *Stroke; A Journal of Cerebral Circulation*, 34(8), 1944-1950. <https://doi.org/10.1161/01.STR.0000081987.46660.ED>
- Hilari, K., Needle, J. J., & Harrison, K. L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation*, 93(1 Suppl.), S86-S95. <https://doi.org/10.1016/j.apmr.2011.05.028>
- Hinckley, J., Kim, E., Koo, H., Rushlow, D., Rushlow, J. C., Van Allen, S., Wallace, S., Bislick, L., Brancamp, T., Caputo, M., Dietz, A., Duncan, E. S., Evans, W., Hambridge, T., & Harmon, T. (2021, November 18-20). *Rising united in research: Multi-stakeholder team updates from Project BRIDGE*. American Speech Language Hearing Association Annual Convention [Platform Presentation].
- Hunting Pompon, R., Amtmann, D., Bombardier, C., & Kendall, D. (2018). Modifying and validating a measure of chronic stress for people with aphasia. *Journal of Speech, Language, and Hearing Research*, 61(12), 2934-2949. https://doi.org/10.1044/2018_JSLHR-L-18-0173
- Kearns, A., Kelly, H., & Pitt, I. (2019). Rating experience of ICT-delivered aphasia rehabilitation: Co-design of a feedback questionnaire. *Aphasiology*, 34(3), 319-342. <https://doi.org/10.1080/02687038.2019.1649913>
- Kelly, G. (2015). Predictors of posttraumatic growth in stroke survivors (Doctoral dissertation). *Dissertation Abstracts International* (Accession No. 10179285).
- Kelly, G., Morris, R., & Shetty, H. (2018) Predictors of post-traumatic growth in stroke survivors. *Disability and Rehabilitation*, 40(24), 2916-2924. <https://doi.org/10.1080/09638288.2017.1363300>
- Kuenemund, A., Zwick, S., Rief, W., & Exner, C. (2016). (Re-)defining the self-enhanced posttraumatic growth and event centrality in stroke survivors: A mixed-method approach and control comparison study. *Journal of Health Psychology*, 21(5), 679-689. <https://doi.org/10.1177/1359105314535457>
- Linte, C. A. (2009). Communicating your research in lay language. *IEEE Engineering in Medicine and Biology Magazine*, 28(3), 5-7. doi: 10.1109/memb.2009.932488
- Locock, L., & Boaz, A. (2019). Drawing straight lines along blurred boundaries: Qualitative research, patient and public involvement in medical research, co-production and co-design. *Evidence & Policy*, 15(3), 409-422. <https://doi.org/10.1332/174426419x15552999451313>
- Mackay, R. (2003). 'Tell them who i was'[1]: The social construction of aphasia. *Disability & Society*, 18(6), 811-826. <https://doi.org/10.1080/0968759032000119532>
- McMenamin, R., Isaksen, J., Manning, M., & Tierney, E. (2022). Distinctions and blurred boundaries between qualitative approaches and public and patient involvement (PPI) in research. *International Journal of Speech-Language Pathology*, 24(5), 515-526. <https://doi.org/10.1080/17549507.2022.2075465>

- National Institutes of Health. (2022). *Plain language*. <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language>
- Nätterlund, B. S. (2010). Being a close relative of a person with aphasia. *Scandinavian Journal of Occupational Therapy, 17*(1), 18–28. <https://doi.org/10.3109/11038120902833218>
- Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology, 21*(1), 98–123. <https://doi.org/10.1080/02687030600798337>
- Patient-Centered Outcomes Research Institute. (2022). *Building effective multi-stakeholder research teams*. <https://research-teams.pcori.org>
- Paul, D. R., Frattali, C. M., Holland, A. L., Thompson, C. K., Caperton, C. J., & Slater, S. C. (2004). *Quality of Communication Life Scale*. American Speech Language Hearing Association.
- Peng, Z.-Y., & Wan, L.-H. (2018). Posttraumatic growth of stroke survivors and its correlation with rumination and social support. *Journal of Neuroscience Nursing, 50*(4), 252–257. doi:10.1097/JNN.0000000000000371
- Readability Formulas. (2022). *Free readability tools to check for reading levels, reading assessment, and reading grade levels*. <https://www.readabilityformulas.com>
- Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2011). Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology, 13*(4), 335–347. <https://doi.org/10.3109/17549507.2011.560396>
- Rose, T. A., Worrall, L. E., & McKenna, K. T. (2003). The effectiveness of aphasia-friendly principles for printed health education materials for people with aphasia following stroke. *Aphasiology, 17*(10), 947–963. <https://doi.org/10.1080/02687030344000319>
- Salis, C., Kelly, H., & Code, C. (2015). Assessment and treatment of short-term and working memory impairments in stroke aphasia: A practical tutorial. *International Journal of Language & Communication Disorder, 50*(6), 721–736. <https://doi.org/10.1111/1460-6984.12172>
- Shadden, B. B., & Agan, J. P. (2004). Renegotiation of identity: The social context of aphasia support groups. *Topics in Language Disorders, 24*(3), 174–186. <https://doi.org/10.1097/00011363-200407000-00005>
- Shadden, B. B., & Koski, P. R. (2007). Social construction of self for persons with aphasia: When language as a cultural tool is impaired. *Journal of Medical Speech-Language Pathology, 15*(2), 99–106.
- Shakespeare-Finch, J. E., & Lurie-Beck, J. (2014). A meta-analytic clarification of the relationship between posttraumatic growth and symptoms of posttraumatic distress disorder. *Journal of Anxiety Disorders, 28*, 223–229. <https://doi.org/10.1016/j.janxdis.2013.10.005>
- Sherratt, S., & Worrall, L. (2019). *Changing and growing: An exploration of posttraumatic growth narratives in aphasia*. Research Gate. [Preprint]. April 8, 2019. <https://doi.org/10.13140/RG.2.2.24767.97446>
- Sherratt, S., & Worrall, L. (2020). Posttraumatic growth following aphasia: A prospective cohort study of the first year post-stroke. *Aphasiology, 35*(3), 291–313. <https://doi.org/10.1080/02687038.2020.1787945>
- Shiggins, C., Coe, D., Gilbert, L., Mares, K., & Aphasia Research Collaboration. (2022a). Development of an “Aphasia-Accessible Participant in Research Experience Survey” through co-production. *Aphasiology, 1*–34. <https://doi.org/10.1080/02687038.2021.1996532>
- Shiggins, C., Ryan, B., O’Halloran, R., Power, E., Berhardt, J., Lindley, R. I., McGurk, G., Hankey, G. J., & Rose, M. (2022b). Toward the consistent inclusion of people with aphasia in stroke research irrespective of discipline. *Archives of Physical Medicine & Rehabilitation, 103*(11), 2256–2263. <https://doi.org/10.1016/j.apmr.2022.07.004>
- Simmons-Mackie, N. (2018). *Aphasia in North America: frequency, demographics, impact of aphasia, communication access, services and service gaps*. Aphasia Access.
- Simmons-Mackie, N., Kagan, A., Victor, J. C., Carling-Rowland, A., Mok, A., Hoch, J. S., Huijbregts, M., & Streiner, D. L. (2014). The assessment for living with aphasia: Reliability and construct validity. *International Journal of Speech-Language Pathology, 16*(1), 82–94. <https://doi.org/10.3109/17549507.2013.831484>
- Tedeschi, R. G., & Calhoun, L. G. (1996). The post-traumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*(3), 455–471. <https://doi.org/10.1007/BF02103658>
- Tedeschi, R. G., Shakespeare-Finch, J., Taku, K., & Calhoun, L. G. (2018). *Posttraumatic growth: Theory, research, and application*. Routledge.
- Vickers, C. P. (2010). Social networks after the onset of aphasia: The impact of aphasia group attendance. *Aphasiology, 24*(6–8), 902–913. <https://doi.org/10.1080/02687030903438532>