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Co-design of the aphasia research library: a web-based platform and searchable repository for customisable, accessible research summaries

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ABSTRACT

Background: Researchers have an ethical obligation to make their findings accessible to the communities they serve, and this imperative is increasingly reflected in funding and institutional requirements. Plain language summaries (PLS) are commonly developed alongside traditional outputs to meet this need. Many, however, fail to support diverse communication needs and lack infrastructure for independent discovery and access.

Aims: The original aim was to establish the preferences of people with aphasia regarding the content and format of PLS, and to co-design a communication-accessible PLS template. The participatory process redirected these aims, as described below.

Methods and Procedures: A mixed-methods design was employed using the double diamond co-design framework, with Consumer and Community Involvement embedded across

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four phases: discover, define, develop, and deliver. In the discover phase, the concept was presented at an online aphasia forum co-hosted by Dyscover and Speakeasy, UK-based aphasia consumer organisations. In the define phase, an international multimodal multilingual survey was used to prioritise research summary content domains. Data were analysed using descriptive statistics and qualitative content analysis. In the develop and deliver phases, a solution: the Aphasia Research Library, was iteratively co-designed in workshops and developed in sprints.

Outcomes and Results: An online forum (discover phase; approximately 30 people with aphasia and family members) established unanimous agreement on the need for accessible research summaries in a single searchable location. An international survey of 70 people with aphasia across 15 countries and 11 languages (define phase) prioritised research aims, results, and implications as essential content domains. Three co-design workshops with four people living with aphasia (develop and deliver phases) identified that a document-based template could not meet needs for personalisation, persistent access, and self-directed discovery, redirecting the project from a template to a platform. The Aphasia Research Library (ARL; www.aphasialibrary.org) is a freely available web-based searchable database. For people with aphasia, the ARL offers a customisable interface with adjustable display settings, text-to-speech conversion, and an integrated plain language dictionary. For researchers, it provides a structured input template with automated readability ratings and a permanent, shareable link.

Conclusions: The ARL addresses both communicative and structural barriers to research access for people with aphasia. The co-design process demonstrates that genuine consumer involvement does not merely refine researcher-led solutions but can fundamentally redefine a problem and its solution. Future directions include integration of artificial intelligence and expansion of multilingual functionality.

Introduction

Plain language summaries (PLS) are essential knowledge-translation tools that present research findings in accessible, non-technical language for readers without an academic background (Stoll et al., 2022; Zarshenas et al., 2023). Typically accompanying a peer-reviewed journal article, they use everyday vocabulary, avoid jargon and acronyms, and target reading levels accessible to the general public. In Australia, for example, writing to a year 7 level is recommended to ensure written content is accessible for most people (Australian Government, n.d.). PLS typically cover the research problem, study aims, design and methods, key findings, and implications for practice or future research (Hinckley & El-Khouri, 2023). The importance of PLS is well established: equitable access to research supports health literacy and informed decision-making and underpins trust in and accountability for publicly funded research (Day et al., 2020). PLS are also effective: research findings in plain language formats improve understanding, accessibility, usability, and satisfaction with health information (Sayfi et al., 2024). PLS and related formats, such as graphical and video abstracts, are increasingly recommended or required

alongside traditional research outputs, reflecting a growing consensus that researchers have an ethical obligation to make their findings accessible to the communities they serve (Hersh et al., 2025; Hinckley & El-Khouri, 2023).

Despite increasing uptake, PLS, as currently produced, do not meet the access needs of many readers. Guidance for producing PLS is largely premised on the communication needs of the general public, but people with literacy difficulties, cognitive impairment, or communication disability have different needs and preferences (Finch et al., 2024; Jackson et al., 2025; Meltzer et al., 2025). For people with communication disabilities, including those with aphasia, written language, even when simplified to recommended readability levels, can still present a significant barrier. The heterogeneous impacts of aphasia across language modalities mean that even carefully written plain language text may be inaccessible without additional communication supports (Aleligay et al., 2008). Communication accessibility can be conceptualised similarly to physical accessibility: just as environmental modifications such as ramps remove barriers to physical inclusion, modifications to communication formats can remove barriers to information access (Brown et al., 2021; van Rijssen et al., 2023). People with aphasia want access to information, including research findings (T. Rose et al., 2020), and this access is a matter of equity.

Evidence supports the value of aphasia-friendly modifications to written information. Guidance exists for making written health information accessible for people with aphasia, recommending simplified syntactic structures, everyday vocabulary, larger text, bolded keywords, white space, and the use of images to support written text (Herbert et al., 2012, 2019; T. A. Rose et al., 2011). Communicatively accessible or "aphasia-friendly" formats are both preferred by people with aphasia (T. A. Rose et al., 2011) and associated with improved understanding of health information (T. Rose et al., 2003; Saylor et al., 2022). Beyond written formats, people with aphasia benefit from multimodal communication, in which visual supports, gestures, facial expressions, and tone supplement written or spoken language to enhance comprehension (Pierce et al., 2019). These principles have begun to be applied to research dissemination, with two recently published tutorial papers providing guidance. Hinckley and El-Khouri (2023) synthesised existing evidence on the rationale, characteristics, and resources for producing aphasia-friendly research summaries. Kasdan, Levy Deborah, et al. (2025) published a practical guide for creating PLS and reported the development of a prototype Artificial Intelligence (AI) tool for generating accessible abstracts. Notably, however, neither involved people with aphasia in development. Kasdan, Levy Deborah, et al. (2025) draw attention to a further gap, a limited focus on implementation: that is, how accessible summaries might reach their intended audience, be independently discovered by people with aphasia, or be retained for future reference.

Consumer involvement is widely recognised as central to implementation success. Without end users shaping how a solution is designed to function in practice, even well-designed outputs risk remaining inaccessible. Recent work in aphasia and developmental language disorders demonstrates the value of such approaches. Finch et al. (2024) explored the preferences of people with aphasia for the format of aphasia research videos. Using a three-stage consultation process, they identified 11 consumer-informed preferences for aphasia research videos, including a normal speaking rate, a duration of 5 to 10 minutes, written keywords, a mix of images, inclusion of a person with aphasia, and a summary at the end. In the field of developmental language disorders, Jackson et al.

(2025) conducted a mixed-methods study to explore how researchers can make their findings more accessible. They found that PLS, infographics, and short videos were preferred, and that community members strongly endorsed involving people with lived experience in developing and presenting research summaries. These findings illustrate both the feasibility of involving end users in accessible dissemination and the importance of consumer-defined priorities for reaching people in practice. The present study extends this approach to written PLS for people with aphasia, addressing the implementation gap through a participatory process that places people with aphasia at the centre of both problem definition and solution design.

The project originated with two researcher-defined aims: (1) to establish the preferences of people with aphasia regarding the content and format of accessible research summaries; and (2) to co-design a communicatively-accessible PLS template with people with aphasia. The initial expectation was that these aims would produce a PLS template for written summaries, refined through consumer input. The participatory process redirected both the form and scope of the solution, with consumer voices reframing the problem from one of document design to one of infrastructure, personalisation, and independent access.

Methods

Positionality

This research is grounded in a critical realist ontology (Maxwell, 2022). This position recognises that the experience of living with aphasia and of accessing research is real and consequential, and is shaped by neurological impairment, the communication environment, and social context. At the same time, we acknowledge that such experiences are always mediated through language, relationships, and the structure of the research encounter. Access to research is further constrained by structural barriers that exist independently of communication disability: paywalls, institutional subscription requirements, reliance on digital access, and the concentration of research dissemination within academic publishing ecosystems (Day et al., 2020). These barriers mean that even people without communication disability are routinely excluded from evidence generated about their own health conditions. For people with aphasia, communication, environmental and structural barriers compound one another, excluding them from knowledge ostensibly produced in their interest.

A constructivist epistemology followed from this position: knowledge about the accessibility needs of people with aphasia was understood as co-produced between researchers and people with lived experience. This shaped both our methodology and the design of our solution, motivating genuine power-sharing in the co-design process and a non-negotiable commitment to inclusive, accessible, and customisable design.

Reflexivity

The lead researcher (SJW) entered this project with a clear preconception: that the aim was to develop a PLS template for people with aphasia. This assumption was shaped by familiarity with existing guidance, and by an implicit belief that the barriers to accessible

research dissemination were primarily problems of document design. The expectation was that consultation would confirm this direction and inform the template's specifications. Instead, the participatory process fundamentally challenged this framing. Consumer voices in the online forum and the co-design workshops identified barriers that a well-designed template could not address: the absence of a searchable, centralised repository; the impossibility of personalisation within a fixed format; and the lack of infrastructure for people with aphasia to independently discover and return to research over time. These concerns redirected the project entirely, from a template to a technology-based platform, and reshaped what the research ultimately set out to achieve.

Research design

A mixed-methods design was employed using the double diamond co-design framework (Design Council, 2007), which structures participatory design through four phases: discover, define, develop, and deliver. Originally developed by the UK Design Council, the double diamond has been widely adopted in health and human-centred design research as a framework that explicitly separates problem definition from solution generation. Unlike linear research models that move directly from a predefined problem to a solution, the double diamond front-loads a divergent discovery phase focused on establishing what the problem is, opening the problem space broadly before converging on a defined focus. It represents divergence and convergence as distinct modes of work. Within our transdisciplinary team, this provided a shared and readily communicable account of where in the process we were and what kind of contribution was expected at each stage. Consumer and Community Involvement (CCI, also known as patient and public involvement (PPI)) was embedded across all four phases, with the level of involvement varying at each stage. For example, in the discover phase, people with aphasia participated as informants at a community forum; in the define phase, they completed the survey as research participants; and in the develop and deliver phases, three people with aphasia and one family member participated as co-designers with active decision-making roles, while two people with aphasia served as co-investigators across the full project. This is described throughout per the International Association for Public Participation Spectrum of Public Participation (IAP2; 2018). Ethical approval was obtained from The University of Queensland Human Research Ethics Committee (project ID: 2021/HE000797), and all participants provided informed consent prior to participation.

Consumer and community involvement

The initial concept was research-led, as an initiative of the Collaboration of Aphasia Trialists (www.aphasiatrials.org). At the research conceptualisation and planning phase, CCI occurred at the consultation level, by engaging a large group of people with aphasia (approximately 30 people with aphasia and family members) to gauge the proposed project's relevance and to establish initial research directions. At the collaboration level, the team included people living with aphasia and a family member of a person living with aphasia as co-researchers. People living with aphasia (3 people with aphasia and 1 family member) participated as co-designers in the design and development of the Aphasia Research Library (ARL) and are co-authors of this publication. Reporting of CCI follows the

GRIPP2 framework (Guidance for Reporting Involvement of Patients and the Public; Staniszewska et al., 2017; see Supplemental file 1).

Phase 1 Discover: Online Forum Consultation

In the *discover* phase, the process was opened broadly to explore whether and how people with aphasia sought to access research and what barriers they encountered. SJW and KBe were invited to present on the proposed project at an online Aphasia Forum jointly hosted by the UK aphasia organisations Dyscover (https://dyscover.org.uk/) and Speakeasy (https://speakeasy-aphasia.org.uk/) using Zoom in September 2021. The forum was attended by approximately 30 people with aphasia and family members from Australia and the UK, representing various aetiologies, ages, severities, and times since aphasia onset. The forum was a community event, and not research, therefore formal attendance numbers were not recorded nor was consent obtained. Forum attendees opted in to the event through the hosting organisations. Background information about research summaries was provided (SJW and KBe), followed by small group discussions in breakout rooms (approximately three to six participants per group) facilitated by research team members (SJW, CS, BR, BC) and volunteers (see acknowledgements). The whole group then participated in a discussion about the merit and design of subsequent research. Following the forum, attendees received an accessible summary of the discussion and were invited to provide further comments. This information informed the design of the subsequent research phases.

Phase 2 Define: Survey to Establish Preferences for Accessible Aphasia Research Reporting

In the *define* phase, an online survey narrowed the focus of the project, using participant-prioritised data to establish the specific content and format requirements an accessible solution should meet.

Participants and recruitment

Adults with a self-reported history of aphasia by any cause were invited to participate. No incentives were offered. The survey was open for completion between March and June 2022. A convenience sample was recruited via a link on a recruitment advertisement disseminated through social media channels, consumer organisations, and the more than 300 members of the multi-national Collaboration of Aphasia Trialists (www.aphasiatrials.org). All research materials, including the recruitment advertisement and participant information sheets, were formatted using principles of aphasia-friendly written information (Herbert et al., 2012, 2019; T. A. Rose et al., 2011), incorporating simplified syntactic structures and vocabulary, larger text, bolded keywords, and pictorial aids, with an option for voiceover narration. Aphasia-friendly recruitment materials were available in eight languages to enable both people with aphasia and their partners to access the information with minimal or no assistance and make an informed decision about participation. Respondents' IP addresses, location data, and contact information were not recorded.

Table 1. Participant demographic data ($n = 70$).

Age (mean, IQR)	54.3 (42–67)
Years of education (mean, IQR)	19 (16–23)
Biological sex, female (%)	33 (47.1)
Country of residence (n, %)	
Australia	22 (31.4)
United Kingdom	13 (18.6)
China	8 (11.4)
Saudi Arabia	8 (11.4)
United States of America	4 (5.7)
Germany	3 (4.3)
Hong Kong	3 (4.3)
India	2 (2.9)
Canada	1 (1.4)
Chile	1 (1.4)
Finland	1 (1.4)
Ireland	1 (1.4)
Malaysia	1 (1.4)
Spain	1 (1.4)
Switzerland	1 (1.4)
Primary language (n, %)	
English	41 (58.6)
Arabic	8 (11.4)
Mandarin	7 (10.0)
Cantonese	2 (2.9)
German	2 (2.9)
Russian	2 (2.9)
Spanish	2 (2.9)
French	1 (1.4)
Hindi	1 (1.4)
Italian	1 (1.4)
Thai	1 (1.4)
Not specified	2 (2.9)
Aphasia cause (n, %)	
Stroke	52 (74.3)
Head injury	10 (14.3)
Progressive neurological condition	4 (5.7)
Brain tumour	3 (4.3)
Not specified	1 (1.4)
Time post onset (n, %)	
Less than 6 months	7 (10.0)
6 to 11 months	5 (7.1)
1 to 2 years	14 (20.0)
3 to 5 years	17 (24.3)
More than 5 years	26 (37.1)
Not specified	1 (1.4)

Table 1 shows the demographic characteristics of the 70 survey respondents. Participants reported living in 15 countries and speaking 11 languages. Most respondents were from Australia and the UK, followed by China and Saudi Arabia. English was the most frequently reported language spoken at home, followed by Arabic and Mandarin. Aetiology of aphasia spanned stroke, head injury, brain tumour, and progressive neurological conditions. Most respondents (74%) reported aphasia caused by stroke, and 90% were living with chronic aphasia (more than 6 months post onset; $n = 63$).

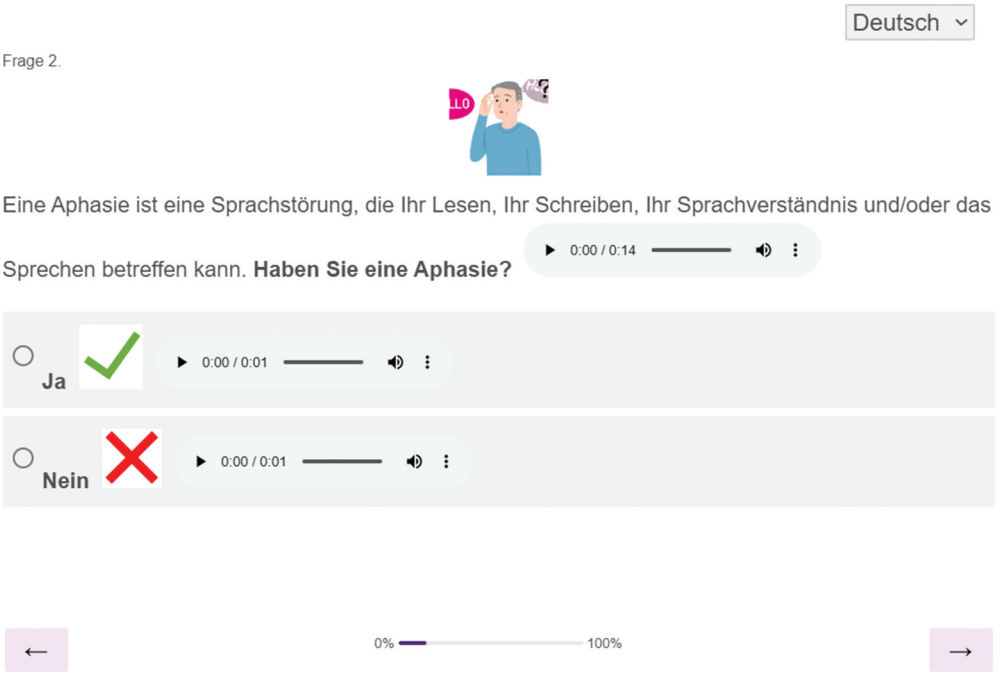


Figure 1. Example of the communication-accessible, multi-lingual survey format.

Survey development

The communicatively accessible online survey (See Figure 1 and Supplemental file 2) was designed and reported with reference to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES; Eysenbach, 2004; see Supplemental file 3) and delivered using Qualtrics (Qualtrics, Provo, UT). The survey was presented in an aphasia-friendly multimodal format to maximise accessibility, incorporating short sentences with simple vocabulary, bolded keywords, bullet points, white space, and images to support text. All written text was accompanied by voiceover audio. Short aphasia-friendly videos presented information and instructions in both written and spoken form and demonstrated survey completion. Participants were advised that individualised real-time assistance from research team members was available via videoconferencing on request.

The survey was initially developed in English (SJW, BC, BR, TR, CS, RP). Revision and refinement of the English version followed an iterative process of internal review and piloting by a reviewer with aphasia with support from their family member (EB, KBe). Pilot feedback identified several usability and navigation issues. Key concerns included the absence of a back button, unclear progression through the survey, and the final two questions perceived as repetitive or unclear. Reviewers recommended clearer signposting at the end of the survey, larger text response boxes, and a memory aid or contextual heading for open-ended questions to help participants stay oriented to the topic. The reviewer with aphasia found the survey easy to follow, the video explanations clear, and the dual written-spoken presentation of information helpful. Following this piloting and refinement process, the survey was translated into Arabic, Bengali, simplified and traditional Chinese (with Cantonese and Mandarin audio), French, German, Hindi, and Spanish

by research team members who are speakers of those languages (CB, MD, AP, RA, APHK, ES, SMF; see Figure 1 for an example of the German version).

Survey data

The survey collected: (1) participant demographics, aligned with the DESCRIBE checklist of descriptors for participants with aphasia (Wallace et al., 2023); (2) self-ratings on a 4-point Likert scale of difficulty experienced talking, understanding, writing, and reading; (3) responses on a prioritisation task; and (4) open-ended questions about accessible research reporting. Questions were presented across 19 pages in Qualtrics. The prioritisation task asked participants to categorise 21 unique information content items into three priority levels:

- Must have: information that is very important to know.
- Nice to have: information that is interesting but not important.
- No need to have: information that is not important and not interesting.

The 21 items were generated from existing evidence on plain language research reporting and direct input from consumers at the September 2021 Aphasia Forum. Item presentation was randomised.

Survey data analysis

Analysis was performed by SH. Data were exported from Qualtrics into Microsoft Excel (Microsoft Corporation, 2021). Responses containing only consent and/or demographic information were excluded from analysis; responses containing consent and demographic information alongside partial or complete survey responses were included. Descriptive statistics (frequency counts and percentages) were calculated for quantitative data. To explore whether content preferences varied by country or self-reported aphasia severity, chi-squared tests were conducted in R (Version 4.3.1; R Core Team, 2024) for each of the 21 content items, comparing "must have" ratings across subgroups ($\alpha = .05$). Qualitative data from open-ended questions were analysed using conventional qualitative content analysis (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005), a systematic classification process of coding and identifying categories. Responses in languages other than English were translated to English by members of the research team. The survey included one open-ended question inviting participants to share any further thoughts on the information that should be include in aphasia-friendly research summaries. SH read individual responses, derived codes capturing key meaning, and grouped related codes into categories. Coding was inductive and not guided by the survey structure or predefined categories. Coding was reviewed by SJW. Given the brief, list-like nature of open-ended responses, analytical decisions centred on accurate representation of respondent meaning rather than interpretive inference. Reflexivity was supported through discussion between SH and SJW to ensure that codes reflected the language and intent of respondents rather than researcher-imposed frameworks.

Phases 3 and 4 Develop and Deliver: Co-design of an Accessible Research Reporting Solution

In the *develop* phase, co-design workshops generated and explored a range of design options in partnership with people with lived experience before a framework was agreed upon. In the *deliver* phase, the agreed design was realised through iterative development sprints and user experience testing, culminating in the launch of the ARL.

Co-designers

Four people living with aphasia (3 people with aphasia and 1 family member) affiliated with the Queensland Aphasia Research Centre were invited to be involved as co-designers. Co-designers brought diversity in gender, age, and aetiology of aphasia (post-stroke and progressive). They were offered an AUD $100 voucher on completion of the project to acknowledge their time and contributions.

Facilitators

The co-design process was facilitated by an experienced aphasia researcher and speech pathologist (SJW), an interaction designer with experience working with people with communication support needs (PW), a software developer (RD), and a speech pathologist and research assistant (BB). Methodological support was provided by CS.

Activities

Three co-design workshops were held, each approximately 2 hours in duration with multiple breaks, interspersed with development sprints (short, focused bursts of work where the team completed a specific set of tasks). Workshops were recorded via Zoom to support the development of communicatively-accessible meeting minutes, which were disseminated to co-designers following each session. Four principles for co-design (McKercher, 2020) were adhered to across all workshops:

- Sharing power and empowering people with aphasia in decision-making to ensure meaningful engagement in the research process.
- Prioritising relationships to develop trust.
- Using participatory and multimodal means to support active engagement, including visual, kinaesthetic, and oral and non-verbal approaches.
- Building capability by supporting co-designers to have their voices heard.

Workshop 1 The first workshop focused on establishing a supportive and inclusive environment and orienting co-designers to the research context, co-design process, and their role. Results from the online forum and international survey were presented to ground subsequent discussions in the priorities and preferences of the broader aphasia community. Co-designers viewed a prototype of an "aphasia-friendly" document generator developed by the facilitation team as a provocation (an idea to challenge assumptions; see Figure 2). The document generator tool comprised a researcher-facing input form with a live preview of the resulting "aphasia-friendly" summary. They then worked together to generate ideas in response to three questions:

- What should our research summary look like?
- What features should it have?
- How should it be used and accessed?

Workshop 2 The second workshop opened with a structured recap of key design considerations from Workshop 1 (see results). Co-designers reviewed a prototype web page focused on customisation of content preferences and reviewed corresponding summary outputs (see Figure 3). The group discussed the prototypes and prioritised directions for the subsequent development sprint.

Workshop 3 The third workshop opened with a structured recap of key design considerations from Workshop 2, before co-designers evaluated a refined version of the platform through practical examples of how it might look and function in use (See Figure 4). Next steps for development and dissemination were discussed before a final review and endorsement of the design.

Results

Phase 1 Discover: Online Forum Consultation



Figure 2. Workshop 1 document generator prototype.

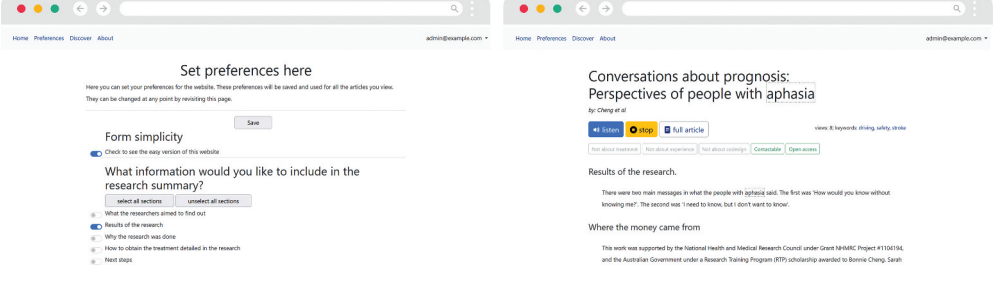


Figure 3. Workshop 2 prototype content preferences and corresponding summary output.

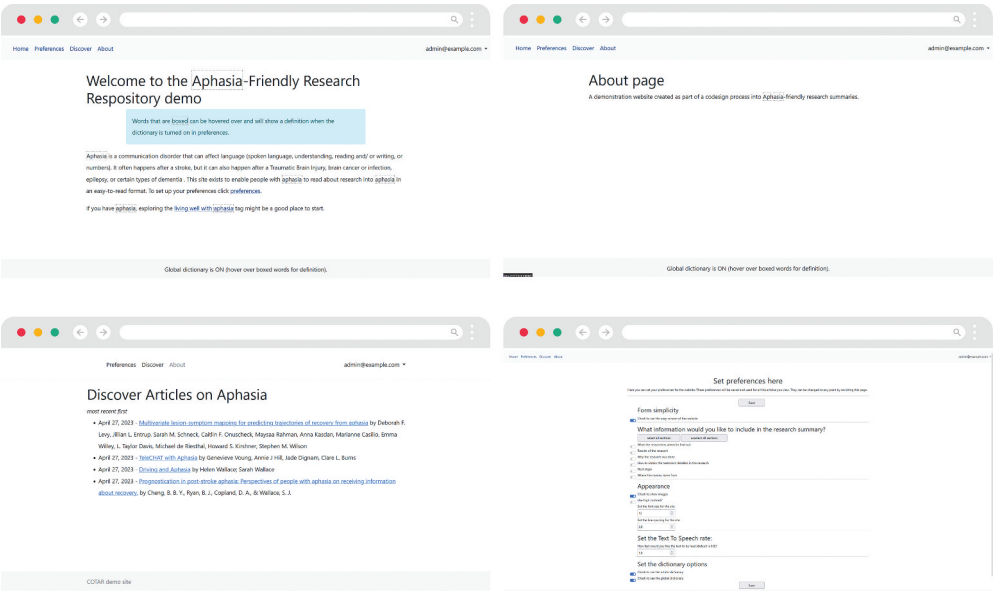


Figure 4. Workshop 3 prototype platform pages.

Forum attendees unanimously agreed that accessible research summaries are needed, particularly for studies reporting on issues that directly affect people with aphasia, including how to live well with aphasia, aphasia treatments (such as which interventions work and how much therapy is needed), and related research areas (such as upper limb rehabilitation, physiotherapy, occupational therapy). Attendees indicated it was important to be able to share research summaries with other people with aphasia, family members, friends, speech pathologists, and aphasia peer support groups and organisations, both in person and through online channels (such as email and social media). They said research summaries were important for raising awareness about aphasia, to have hope from knowing what research is happening, to feel involved and to be aware of opportunities to contribute to research.

Regarding content, attendees agreed the template should include information that helps readers understand and contextualise the research, including details about the participants (such as sample size, age, and cause and severity of aphasia) and the study itself (such as study type, limitations, and whether people with aphasia were involved as researchers). The summary should avoid jargon, abbreviations, excessive background information, superfluous detail, and unnecessary complexity. Attendees also provided preferences regarding the appearance of summaries including that they should be in an "aphasia friendly" format, with multiple modes (e.g., audio), and stored in a "one-stop shop", that is that research summaries should be stored in a single, searchable online location.

Phase 2 Define: Survey to Establish Preferences for Accessible Aphasia Research Reporting

There were 70 complete survey responses from 141 responses received (completion rate = 49.6%). Eleven respondents did not provide any responses and were removed from

the dataset. A considerable number of respondents ($n = 59$) provided demographic data but did not provide responses to the prioritisation tasks and were therefore removed (see Strengths and Limitations for discussion). Seven participants responded "No" to the question "Do you have aphasia?" However, six of these respondents subsequently provided details of their aphasia, such that it was inferred that the initial response was made in error. These six participants' data were included. Data from one respondent who provided no information regarding aphasia was removed. Ultimately, data from 70 respondents were included in the analysis.

Table 2 shows the participants' self-reported severity of talking, understanding, writing, and reading problems. These self-reports indicate that the convenience sample captured a heterogeneous group of participants who experience a range of difficulties across these domains.

Survey respondents' priorities for summary content

Figure 5 shows the prioritised list of the 21 information content items. Most respondents (i.e., at least 36) agreed that the following information is essential: 1) research aims, 2) results, 3) study name, 4) type of research, 5) rationale for research, 6) implications of research for people with aphasia, and 7) the research methods used.

Seventeen respondents (mean age 60, IQR 46–73; 10 male; 7 female) from eight countries (Australia, Chile, China, Germany, Hong Kong, Malaysia, United Kingdom, United States of America) provided additional comments in response to the final question: "What information should be in aphasia friendly research summaries. Is there something else?" Responses were typically brief, consisting of one to three sentences, relating to the survey itself, research summary format, and content. Seven respondents commented on the survey, noting difficulties with the drag-and-drop prioritisation task, screen sizing constraints, and the complexity of some questions. Three respondents commented on the research summary format, reinforcing the need for aphasia-friendly presentation including images. Regarding content, respondents suggested including information about research findings that contradict other studies, specific treatment and medication recommendations, and general information about recovery and coping. Two respondents suggested including the country or region where research was conducted, and one respondent each suggested clearer reporting of participant characteristics, funding sources, and nutrition-related health information. Items relating to participant characteristics, funding, and location were already included in the survey prioritisation task.

Chi-squared tests did not reveal statistically significant differences in content preferences by country or self-reported aphasia severity ($\alpha = .05$), noting small cell sizes for some subgroups. Descriptively, however, some patterns of interest were observed. Aims

Table 2. Self-reported difficulty across four language domains ($n = 70$ participants).

Domain	Not a problem	Mild problem	Moderate problem	Severe problem
Talking	4	26	28	12
Understanding	23	28	17	2
Writing	15	27	18	10
Reading	7	20	26	17

Note: Values indicate the number of participants self-reporting difficulties across language domains.

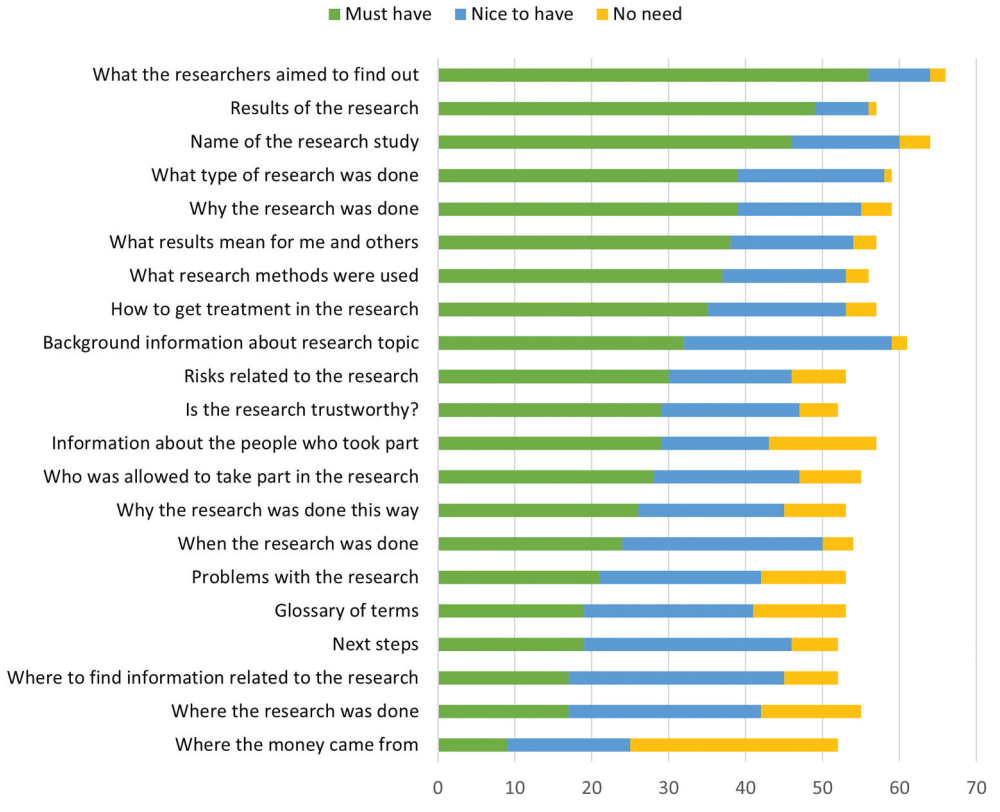


Figure 5. Relative importance of information content items, ordered by priority.

and Results were consistently rated as "must have" across all countries and severity levels, with no country falling below 50% for either item, suggesting these represent near-universal priorities. Saudi Arabian respondents ($n = 8$) more frequently rated "How to get treatment" as a "must have" (88%) compared to respondents from other countries (44%), and similarly prioritised information about participants (75%). Regarding severity, people reporting more severe writing difficulties were more likely to rate "How to get treatment" as a "must have". No consistent severity trends were observed for talking or understanding difficulties.

Phases 3 and 4 Develop and Deliver: Co-design Workshops

Workshop 1 (14 April 2023). Through discussion of forum and survey findings and review of the document generator prototype, co-designers affirmed that the solution should be aphasia-friendly and accessible to everyday people, focused on what people with aphasia want to know, and grounded in the principle that people with aphasia have the right to access research information to support informed decision-making.

Discussion of the content areas to be included in the summary surfaced a key tension when strong individual preferences emerged across the co-design group. One co-designer felt that knowing who funded the research was essential to trusting its findings, while others considered funding information of low

importance. Lengthy discussion followed, but the group could not resolve which content areas should be prioritised. At this point, our software developer (RD) proposed building functionality that would allow individuals to select the content domains they wanted to see, effectively generating a customised summary for each person. This idea was positively received by the group and formed a pivotal moment in the design process.

With regards to the format of information, the group emphasised the need for text-to-speech functionality, highlighted the value of images and icons for contextualising information, and reaffirmed the need for a single online location for research summaries. By the end of the workshop, there was consensus across the group that a fixed template could not accommodate diverse individual communication profiles or content preferences, lacked infrastructure for storing or searching for summaries, and offered no mechanism for people with aphasia to independently discover, share, or return to research over time. Together, these considerations led to a decision to pivot from a document-based solution to a web-based platform.

Workshop 2 (28 April 2023). Workshop two commenced with a review of the key design considerations from workshop 1:

(1) Where possible, research summaries should be kept short. Co-designers reported that people with aphasia often experience fatigue from reading.
(2) People should have a choice over what they want included in the research summary. There should be potential to customise the research summary. It should be tailored to the individual's communication needs.
(3) Pictures and icons should be used. This can help a broad range of people (not just people with aphasia). It can help "link" information, provide context, and help understanding.
(4) The research summaries should be jargon-free. They should use simple language. There should be access to aphasia-friendly and standard versions. A dictionary tool could define words.
(5) Technology should be used to support these principles. This included: text-to-speech functionality, staggered presentation of information, and search capabilities.

Co-designers reviewed a prototype web page focused on content preference customisation and corresponding summary outputs (see Figure 4; developed between workshop 1 and 2), generating detailed feedback across functionality, accessibility, and navigation.

On functionality, co-designers recommended an integrated dictionary linking clinical terms to plain language definitions, preferring a speech-bubble pop-up format with font and contrast adjustments to ensure definitions stood out from surrounding text. A global dictionary built and maintained by the project team, rather than by individual researchers, was proposed as a more efficient and consistent approach, with researchers able to add article-specific terms as needed. Co-designers also recommended a feedback and rating function (e.g., to surface popular summaries), sharing functionality via email, print, and social media, and opt-in push notifications for new uploads. A tagging function to aid discoverability was proposed, alongside a preferences interface using first-person prompts such as "Show me . . ." or "I want to see . . ." to support orientation and agency.

On accessibility, recommendations included larger interactive targets, options to adjust font size, line spacing, and contrast, and intentional and consistent use of colour. Co-designers requested that font size and spacing controls be displayed prominently on the preferences page and expressed a preference for a slower default text-to-speech rate that users could then adjust. Discussion of motor access raised the needs of users with hemiparesis, Parkinson's disease, or essential tremor, prompting a recommendation to enlarge interactive targets (e.g., the X to close the page). The possibility of voice input was raised as a future consideration.

On navigation, co-designers noted that searching through preferences can itself be fatiguing for people with aphasia and recommended that the platform minimise cognitive burden throughout. Discussion of author information generated strong interest, with co-designers enthusiastic about linking author names to institutional profiles and publication lists, though they cautioned against "overlinking", noting that multiple navigational exits can be disorienting for people with aphasia.

Workshop 3 (19 May 2023). Workshop three commenced with a review of the key design considerations from workshop 2:

(1) Design: Font size should be large, titles and information should be bolded, important information could be in a different colour, presentation style should be consistent, and pop-up speech bubbles could be used.
(2) Functionality to provide feedback on research summaries: the capability to rate the summary was discussed but dismissed as essential.
(3) Ability to share information and research summaries via email, print and social media. Summaries should have a link to the full journal article. Users could receive notifications when new research is available.

Co-designers reviewed prototypes of specific platform pages, including the home page, preferences page, about page, and discovery page (see Figure 5).

Feedback on the home page was positive: co-designers found the wording appropriately pitched and the double line spacing easy to read and requested that text-to-speech functionality be accessible from the first page. On the preferences page, co-designers recommended simplifying terminology (for example, using "small, medium, large" for font size and "standard" and "large" for spacing) and replacing technical labels with more intuitive alternatives such as "aphasia-friendly view". They recommended that three clear content display options be offered: see everything, see the simplest version, or let me choose. Co-designers requested that preferences be saved across sessions so that users are not required to reconfigure settings each time they visit. They raised the possibility of a query or portal function allowing users to search for research on specific topics and suggested adding a "contact author" button and feedback link on the author page. On the discovery page, co-designers confirmed that full author names should always be displayed, including in the simplified view, to appropriately acknowledge contributors. They recommended that the text-to-speech listen and stop buttons adopt a red-and-green colour convention for intuitive recognition, and that the button toggle between listen and stop states like an on/off switch. Co-designers confirmed that the current amount and display of article content was appropriate and not too busy, and

noted that colour coding was useful for separating sections. On the author page, co-designers recommended removing acronyms.

The Aphasia Research Library

The co-design process produced the Aphasia Research Library (ARL; www.aphasialibrary.org), a freely available web-based platform and searchable database for communication-accessible research reporting (see Figures 6 and 7).

The ARL incorporates distinct features for people with aphasia and for researchers. For people with aphasia, the ARL offers customisation of both format and content. Format customisation includes adjustment of font size, line spacing, and contrast, and text-to-speech functionality with options to change voice and speech rate. A dictionary function allows users to hover over key words to access a plain language definition, with the option to toggle the function on or off. Users can customise summary content by selecting

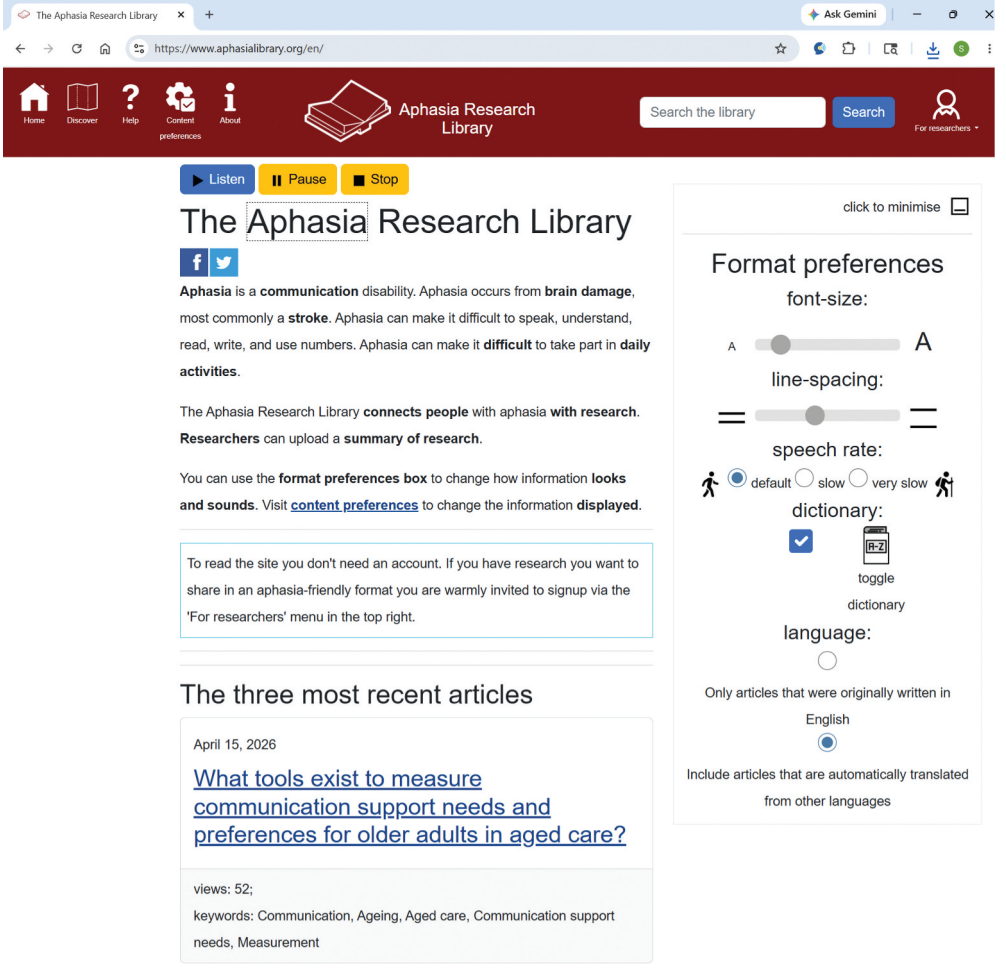


Figure 6. The aphasia research Library (ARL) home page.

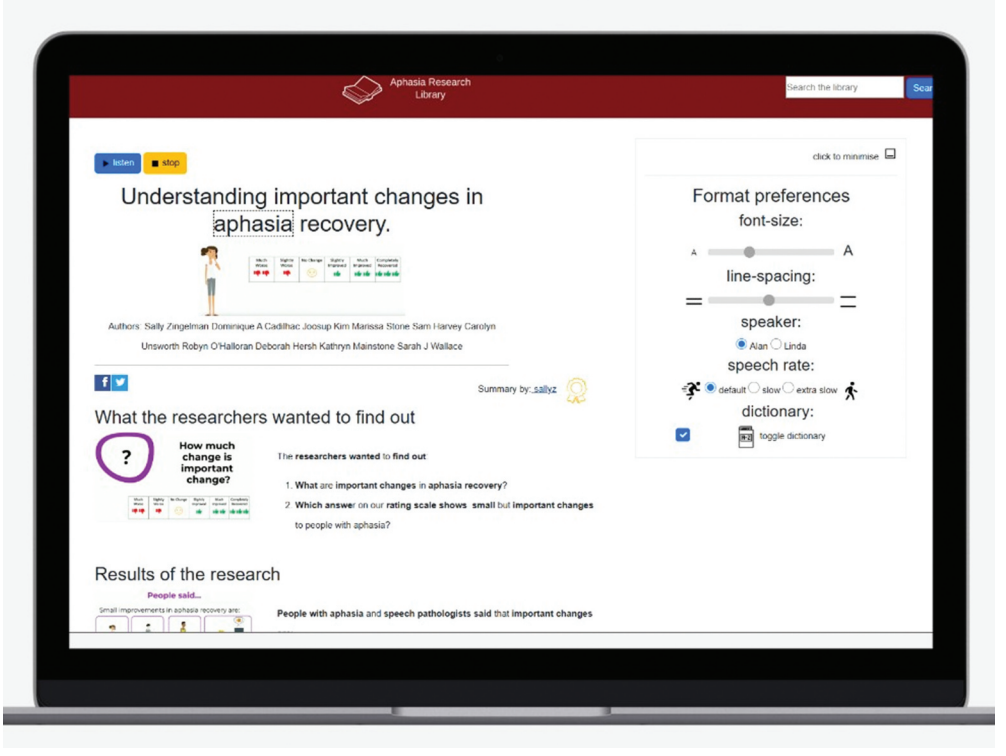


Figure 7. Example ARL Summary.

a short version, a complete version, or choosing specific sections to view. Co-designers also agreed on the platform name, favouring "Aphasia-friendly Research Library" over "Aphasia-friendly Research Repository" on the basis that a library is more intuitively visualised. This was subsequently shortened to the Aphasia Research Library.

For researchers, the ARL provides a structured input template for creating and uploading research summaries (see Figure 8 for example fields). Features include the ability to create an account (required for summary upload), add or view a summary, access tips for writing accessible summaries, define key words within the article, upload images, and link directly to the main article. An automated Flesch-Kincaid readability rating is generated at the point of summary entry to support accessible writing. Critically, the ARL provides a permanent, shareable link to an electronic aphasia-friendly summary, supporting persistent, on-demand access to research for people with aphasia. Researchers are required to create a free account to upload summaries; no account is required to read or search the library.

Following the co-design workshops, translation functionality was developed for Spanish and German, with accuracy reviewed by members of the authorship team proficient in those languages and English (SMF and CB). The platform was also audited for accessibility against the Web Content Accessibility Guidelines (WCAG 2.1 Level AA; see https://www.w3.org/WAI/WCAG2AA-Conformance). The ARL is currently partially conformant with this standard. Known areas of non-conformance include form labelling in the researcher-facing article entry interface, error highlighting when saving drafts, inconsistent provision

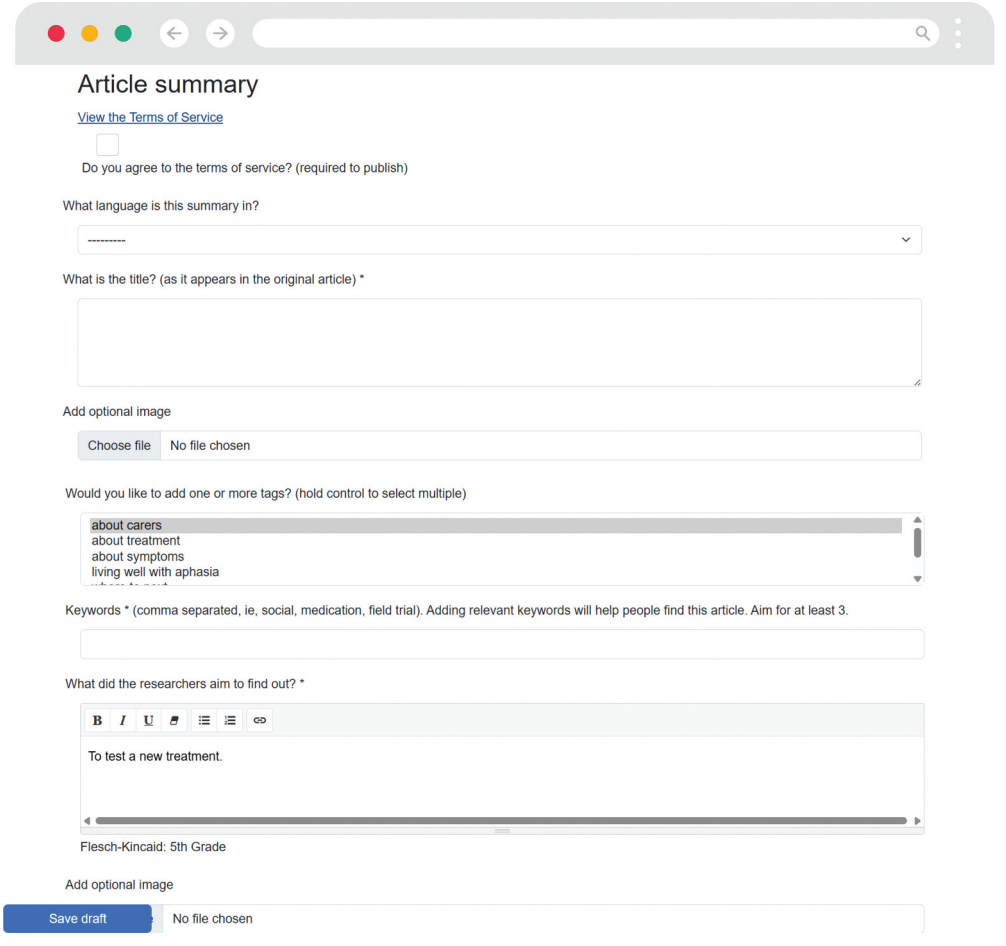


Figure 8. ARL structured input template for researchers.

of alternative text for researcher-uploaded images, and limitations in site-wide navigation (the search function currently indexes articles only). These limitations are documented in the platform's publicly available accessibility statement and represent priorities for future development.

Discussion

We used the double diamond co-design framework to establish the preferences of people with aphasia for accessible research summaries and to co-design a solution for communicatively-accessible research reporting. The result was the Aphasia Research Library, a freely available web-based platform and searchable database that enables researchers to share customisable, communication-accessible research summaries with people with aphasia and the broader community. The co-design process was transformative. The project originated as a researcher-led initiative with a specific and bounded aim: to develop a PLS template for people with aphasia, optimising its content and format.

Consultation with people with aphasia in the forum phase challenged this framing, surfacing needs that a template alone could not address, most notably, the call for a single searchable online location where research could be stored and independently discovered. The subsequent co-design workshops extended and deepened this redirection. Co-designers raised the impossibility of a fixed format meeting heterogeneous communication needs, calling instead for personalisation. They identified the need for persistent, self-managed access to research as a right, not a convenience. What began as a question of document design became a question of infrastructure. The result was not a template, but a technology-based solution shaped by and for people with aphasia, demonstrating that genuine participatory design can produce substantively different outcomes from researcher-led design.

The transformation from paper template to online platform is a key finding in itself. Co-designers identified fundamental limitations of static paper formats, including the absence of searchability, the inability to customise or update content, and limited shareability. This direction was signalled throughout the research project: in the earliest research stages when forum participants called for a single online location for research summaries, in the survey when participants showed variability in content preferences, and in the workshops when co-designer choices preferred customisation. This pivotal design decision was made by people with aphasia, not researchers, reflecting McKercher's (2020) principle of genuine power-sharing in co-design. Our findings suggest that researchers must enter co-design open to more than just the refinement of a predetermined solution; rather, they must be prepared for a profound reframing of the project itself. In this study, genuine engagement required both an epistemological shift in whose knowledge directed the work and an ontological shift in how the core problem was defined, ultimately requiring us to fundamentally reorient our research direction. The implications extend beyond aphasia. Accessible research dissemination cannot be solved by document design alone. Infrastructure for discovery, retrieval, and personalisation is equally important. Permanent online access was therefore a central design feature of the ARL, addressing a recognised gap in PLS hosting and dissemination infrastructure (FitzGibbon et al., 2020; Rosenberg, 2022). Persistent, citable identifiers for PLS have been identified as best practice by multiple stakeholders (Rosenberg, 2022). Unlike a paper summary distributed at a health service or attached to a discharge summary, a permanent URL can be shared between peers, bookmarked, returned to, and updated as evidence evolves. This is particularly significant for people with aphasia, who may require multiple exposures to information and benefit from revisiting content at their own pace and in their preferred modality (Finch et al., 2024; T. Rose et al., 2010). However, people with aphasia face a documented digital divide, with greater avoidance of online health services due to the language demands of standard web content (Menger et al., 2020). The ARL was designed to address that barrier directly, providing accessible web infrastructure and accessible content within a single integrated solution. The searchable database further supports autonomous access: users are not reliant on a clinician or carer to locate and distribute relevant summaries, supporting self-management and autonomy.

A second key design outcome was a customisable template allowing users to select their content and communication format preferences, explicitly rejecting a one-size-fits-all approach. Survey participants' content priorities broadly aligned

with the content domains recommended by Hinckley and El-Khouri (2023). Among the highest-rated items were "What the researchers aimed to find out", "Results of the research", and "What results mean for me and others", which correspond directly to Hinckley and El-Khouri's core recommended elements of research question, results, and implications. Participants also rated "How to get treatment in the research" moderately highly, and this was particularly important to some participant sub-groups. Again, this is consistent with Hinckley and El-Khouri's recommendation to include information about accessing the intervention studied. Our survey extends beyond this framework in several respects. Participants rated a broader range of content as only "nice to have" or "not needed", including items relating to research trustworthiness, risks and problems, and information on who took part. Notably, funding transparency ("Where the money came from") ranked lowest, yet generated the strongest disagreement in co-design workshops, suggesting that aggregate rankings alone can obscure meaningful individual variation. This underscores the case for customisation: a summary template built only on majority preferences risks excluding content that matters deeply to some people with aphasia, even when it appears unimportant at the group level. Cross-cultural and severity-based analyses of survey data provide further support for this position. Descriptive patterns suggest that preferences for specific content domains, particularly treatment-related information, varied meaningfully by country and severity of writing difficulty, although no statistically significant differences were found, likely due to sample size limitations. This reinforces the imperative for a customisable platform rather than a standardised template, again highlighting that a solution built only on majority preferences may not meet the needs of people whose priorities differ from the group average.

Co-designers also rejected a universal approach to formatting, highlighting that aphasia impairments vary substantially across individuals in modality, severity, and trajectory. Accordingly, the group was steadfast that no single summary format could adequately serve all people with aphasia. Communication accessibility is not a uniform standard but an individual experience: what is accessible for one person may present barriers for another (T. A. Rose et al., 2011). Critically, the customisation principle emerged from co-designers drawing on their own lived experience, rather than from researcher prescription, reflecting genuine power-sharing in design. The current findings support recommendations to tailor format and content to individual preferences and serve as a reminder that "aphasia-friendly" or accessible communication is not a fixed format (Finch et al., 2024; Kasdan, Levy Deborah, et al., 2025; T. A. Rose et al., 2011, 2012), but a spectrum of supported choices. Customisation also future-proofs the ARL. As a user's communication profile changes over time, which is common in both recovery and progressive conditions, their preferences can change with it. This aligns with social and functional models of disability, where the goal is reducing environmental barriers rather than normalising the individual to fit a fixed standard (World Health Organization, 2001). The customisable architecture may also have applications beyond aphasia for people with a variety of acquired and developmental communication disabilities.

Strengths and limitations

This study has several strengths, including a genuine co-design approach, an international survey sample spanning 15 countries and 11 languages, multilingual and multimodal accessible research materials, inclusion of diverse aphasia aetiologies, and inclusion of people with aphasia as co-investigators and co-authors. The result is a freely available, functional platform. Limitations include the survey convenience sample with uneven geographic distribution. The geographic distribution of the survey sample likely reflects, at least in part, the networks through which recruitment was conducted, including the Collaboration of Aphasia Trialists and the research team's own connections, which are concentrated in Australia and the UK. This may have introduced a systematic sampling bias, and findings should be interpreted with caution with respect to generalisability across other regions and linguistic communities. The survey completion rate warrants comment. A large number of respondents commenced but did not complete the prioritisation task. This may reflect people previewing the survey without intending to complete it; however, it may also indicate that the drag-and-drop format was too cognitively, linguistically, or physically demanding for some participants. Co-designers joined workshops using the devices available to them, and all chose to use desktop computers. Future research should assess usability across different device types. While the ARL is currently available in English, Spanish, and German, most languages represented in the survey sample are not yet supported, limiting reach to speakers of other languages. Enabling further language versions and evaluation of the usability and effectiveness of the ARL for people with aphasia are future research and development directions.

Conclusions

We co-designed and developed the Aphasia Research Library (www.aphasialibrary.org), a web-based platform and searchable database for communication-accessible research reporting. Our participatory approach with people with aphasia transformed the original concept of a paper-based template into a web-based platform, demonstrating the value of such methods and confirming that researchers must enter co-design genuinely open to having foundational assumptions overturned. The freely available ARL supports equitable access to research for people with aphasia by addressing both communicative and structural barriers to knowledge access within a single integrated solution. Future directions include AI-assisted summarisation, expanded multilingual functionality, and investigating additional pathways for identifying and importing research summaries. Future research could also address the accessibility needs of a broader range of people living with stroke-related disabilities, including visual impairment. The ARL is currently hosted on the Australian Research Data Commons (ARDC) Nectar Research Cloud and maintained by authors SJW, RD, and PW; long-term sustainability will require further consideration as the platform grows. The ARL summary for this article is available at: https://www.aphasialibrary.org/en/article/143/.

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Author contributions

CRediT: **Sarah J. Wallace:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing; **Ryan Deslandes:** Conceptualization, Investigation, Methodology, Project administration, Resources, Writing – review & editing; **Bonnie B. Y. Ross:** Conceptualization, Data curation, Investigation, Project administration, Writing – review & editing; **Caterina Breitenstein:** Investigation, Resources, Writing – review & editing; **Silvia Martínez-Ferreiro:** Investigation, Resources, Writing – review & editing; **Emma Beesley:** Conceptualization, Methodology, Writing – review & editing; **Kim Beesley:** Conceptualization, Methodology, Writing – review & editing; **Phill Jamieson:** Investigation, Methodology, Writing – review & editing; **Kim Barron:** Investigation, Methodology, Writing – review & editing; **Brooke Ryan:** Conceptualization, Data curation, Investigation, Writing – review & editing; **Tanya A. Rose:** Conceptualization, Funding acquisition, Investigation, Methodology, Writing – review & editing; **Rebecca Palmer:** Investigation, Methodology, Writing – review & editing; **Bridget Burton:** Data curation, Investigation, Methodology, Project administration, Writing – review & editing; **Anthony Pak-Hin Kong:** Investigation, Methodology, Resources, Writing – review & editing; **Eva Soroli:** Investigation, Methodology, Resources, Writing – review & editing; **Manaswita Dutta:** Investigation, Methodology, Resources, Writing – review & editing; **Reem S. W. Alyahya:** Investigation, Methodology, Resources, Writing – review & editing; **Sam Harvey:** Formal analysis, Investigation, Writing – original draft, Writing – review & editing; **Analisa Pais:** Investigation, Methodology, Resources, Writing – review & editing; **Ciara Shiggins:** Conceptualization, Funding acquisition, Investigation, Methodology, Supervision, Writing – original draft, Writing – review & editing; **Peter Worthy:** Data curation, Formal analysis, Investigation, Methodology, Resources, Software, Supervision, Visualization, Writing – review & editing.

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Data availability statement

De-identified summary data are available upon reasonable request to the corresponding author. Online forum data are not publicly available as participants did not consent to public data sharing. Survey data are not publicly available as the survey was conducted in multiple languages across international sites and individual responses may be identifiable given the small number of respondents in some countries. Co-design workshop recordings and minutes are not publicly available as co-designers did not consent to public sharing of session content.

References

Aleligay, A., Worrall, L. E., & Rose, T. A. (2008). Readability of written health information provided to people with aphasia. *Aphasiology*, *22*(4), 383–407. https://doi.org/10.1080/02687030701415872

Australian Government. (n.d.). *Literacy and access*. Style Manual. https://www.stylemanual.gov.au/accessible-and-inclusive-content/literacy-and-access

Brown, S. E., Brady, M. C., Worrall, L., & Scobbie, L. (2021). A narrative review of communication accessibility for people with aphasia and implications for multi-disciplinary goal setting after stroke. *Aphasiology*, *35*(1), 1–32. https://doi.org/10.1080/02687038.2020.1759269

Day, S., Rennie, S., Luo, D., & Tucker, J. D. (2020). Open to the public: Paywalls and the public rationale for open access medical research publishing. *Research Involvement and Engagement*, *6*(1), 8. https://doi.org/10.1186/s40900-020-0182-y

Design Council. (2007). *A study of the design process*. Design Council. Eleven lessons: Managing design in eleven global companies. https://www.designcouncil.org.uk/our-resources/archive/reports-resources/11-lessons-managing-design-global-brands/

Eysenbach, G. (2004). Improving the quality of web surveys: The checklist for reporting results of internet E-Surveys (cherries). *Journal of Medical Internet Research*, *6*(3), e34. https://doi.org/10.2196/jmir.6.3.e34

Finch, E., Pierce, J. E., Pais, A. M., Dow-Richards, C., Reed, A., Charalambous, M., Matos, M. A., Wallace, S. J., & Breitenstein, C. (2024). Preferences of people with post-stroke aphasia for aphasia research videos: An international project. *Aphasiology*, *38*(4), 758–769. https://doi.org/10.1080/02687038.2023.2229030

FitzGibbon, H., King, K., Piano, C., Wilk, C., & Gaskarth, M. (2020). Where are biomedical research plain-language summaries? *Health Science Reports*, *3*(3), e175. https://doi.org/10.1002/hsr2.175

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Herbert, R., Gregory, E., & Haw, C. (2019). Collaborative design of accessible information with people with aphasia. *Aphasiology*, *33*(12), 1504–1530. https://doi.org/10.1080/02687038.2018.1546822

Herbert, R., Haw, C., Brown, C., Gregory, E., & Brumfitt, S. (2012). *Accessible information guidelines: Making information accessible for people with aphasia*. Stroke Association. https://www.stroke.org.uk/aphasia-accessible-information-guidelines.pdf

Hersh, D., Israel, M., & Shiggins, C. (2025). The ethics of patient and public involvement across the research process: Towards partnership with people with aphasia. *Aphasiology*, *39*(12), 1575–1600. https://doi.org/10.1080/02687038.2021.1896870

Hinckley, J., & El-Khouri, C. (2023). Why and how to publish aphasia-friendly research summaries. *Journal of Communication Disorders*, *104*, Article 106338. https://doi.org/10.1016/j.jcomdis.2023.106338

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

International Association for Public Participation (IAP2). (2018). IAP2 spectrum of Public participation. In *IAP2*. International Federation. https://www.iap2.org/page/pillars

Jackson, E., Wijaya, J., Bhatoolaul, S., Tan, Q. X., & Leitão, S. (2025). Making research accessible to the developmental language disorder community: A mixed methods study using the nominal group technique. *International Journal of Language & Communication Disorders*, *60*(5), e70096. https://doi.org/10.1111/1460-6984.70096

Kasdan, A. V., Levy Deborah, F., Pedisich, I., Wilson, S. M., & Herrington, D. (2025). A practical guide to translating scientific publications into aphasia-friendly summaries. *Perspectives of the ASHA Special Interest Groups*, *10*(3), 719–727. https://doi.org/10.1044/2025_PERSP-24-00141

Maxwell, J. (2022). Critical realism as a stance for designing qualitative research. In U. Flick (Ed.), *Critical realism as a stance for designing qualitative research* (Vol. 2, pp. 142–154). SAGE Publications Ltd. https://doi.org/10.4135/9781529770278.n10

McKercher, K. A. (2020). *Beyond sticky notes: Co-design for real: Mindsets, methods and movements*. Beyond Sticky Notes.

Meltzer, A., Barnes, E., & Wehbe, A. (2025). Easy read… easy english… plain language? Decision-making in the production of 'easy' information in Australia. *Journal of Applied Research in Intellectual Disabilities*, *38*(1), e70021. https://doi.org/10.1111/jar.70021

Menger, F., Morris, J., & Salis, C. (2020). The impact of aphasia on internet and technology use. *Disability and Rehabilitation*, *42*(21), 2986–2996. https://doi.org/10.1080/09638288.2019.1580320

Microsoft Corporation. (2021). Microsoft Excel. https://office.microsoft.com/excel

Pierce, J. E., O'Halloran, R., Togher, L., & Rose, M. L. (2019). What is meant by "multimodal therapy" for aphasia? *American Journal of Speech-Language Pathology*, *28*(2), 706–716. https://doi.org/10.1044/2018_AJSLP-18-0157

R Core Team. (2024). *R: A language and environment for statistical computing*. R Foundation for Statistical Computing. https://www.R-project.org/

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., Waterson, J., & Caird, E. (2020). The communication research registry: Facilitating access to research experiences for people with a communication disability. *Speech, Language and Hearing*, *23*(4), 208–220. https://doi.org/10.1080/2050571X.2020.1721650

Rose, T., Worrall, L., Hickson, L., & Hoffmann, T. (2010). Do people with aphasia want written stroke and aphasia information? A verbal survey exploring preferences for when and how to provide stroke and aphasia information. *Topics in Stroke Rehabilitation*, *17*(2), 79–98. https://doi.org/10.1310/tsr1702-79

Rose, T., Worrall, L., & McKenna, K. (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

Rosenberg, A. (2022). Working toward standards for plain language summaries. *Science Editor*, *45*(2), 46–50. https://doi.org/10.36591/SE-D-4502-46

Sayfi, S., Charide, R., Elliott, S. A., Hartling, L., Munan, M., Stallwood, L., Butcher, N. J., Richards, D. P., Mathew, J. L., Suvada, J., Akl, E. A., Kredo, T., Mbuagbaw, L., Motilall, A., Baba, A., Scott, S. D., Falavigna, M., Klugar, M., Friessová, T., & Pottie, K. (2024). A multimethods randomized trial found that plain language versions improved adults understanding of health recommendations. *Journal of Clinical Epidemiology*, *165*, 111219. https://doi.org/10.1016/j.jclinepi.2023.11.009

Saylor, A., Wallace, S. E., Brown, E. D., & Schreiber, J. (2022). Aphasia-friendly medication instructions: Effects on comprehension in persons with and without aphasia. *Aphasiology*, *36*(3), 251–267. https://doi.org/10.1080/02687038.2021.1873907

Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., & Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. *BMJ*, *358*, j3453. https://doi.org/10.1136/bmj.j3453

Stoll, M., Kerwer, M., Lieb, K., & Chasiotis, A. (2022). Plain language summaries: A systematic review of theory, guidelines and empirical research. *PLOS ONE*, *17*(6), e0268789. https://doi.org/10.1371/journal.pone.0268789

van Rijssen, M., Isaksen, J., Vandenborre, D., Veldkamp, M., Bryon, E., Remijn, L., Visser-Meily, A., Gerrits, E., & van Ewijk, L. (2023). Ways to improve communication and support in healthcare centres according to people with aphasia and their relatives: A Dutch perspective. *Aphasiology*, *37*(1), 69–82. https://doi.org/10.1080/02687038.2021.1988505

Wallace, S. J., Isaacs, M., Ali, M., & Brady, M. C. (2023). Establishing reporting standards for participant characteristics in post-stroke aphasia research: An international e-Delphi exercise and consensus meeting. *Clinical Rehabilitation*, *37*(2), 199–214. https://doi.org/10.1177/02692155221131241

World Health Organization. (2001). *International classification of functioning, disability and health*. WHO.

Zarshenas, S., Mosel, J., Chui, A., Seaton, S., Singh, H., Moroz, S., Khan, T., Logan, S., & Colquhoun, H. (2023). Recommended characteristics and processes for writing lay summaries of healthcare evidence: A co-created scoping review and consultation exercise. *Research Involvement and Engagement*, *9*(1), 121. https://doi.org/10.1186/s40900-023-00531-5