

# People with Aphasia

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People with Aphasia (PWA) are individuals who experience difficulties in one or more aspects of communication, such as the ability to speak, understand, read and write, due to acquired brain damage (e.g. stroke, dementia, brain tumour, traumatic brain injury).

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## 1. Definition

Research and medical attention are primarily focused on the areas of primary and secondary prevention, acute management, and early rehabilitation of stroke. The neurological sequelae of stroke bring about many issues for the stroke survivor to deal with, such as maintaining relationships, issues with self-confidence, managing finances, cognitive disorders, and communication difficulties due to aphasia. Aphasia affects approximately 20% of chronic stroke survivors and impacts on one or more areas of communication such as the ability to speak, understand, read, and write. Aphasia is linked to poorer functional recovery, return to work, and activities of daily living and leads to fewer friendships, smaller social networks, and reduced quality of life (QoL).

## 2. PWA Involved in the Creation of Quality of Life and Aphasia Impact-Related Questionnaires

In the past decade, researchers in healthcare have shifted their attention to issues closely related to the patient's needs and desires, by engaging patients as co-researchers and research partners in studies through the patient and public involvement (PPI) approach as opposed to passive study participants<sup>[1]</sup>. According to the National Institute of Health Research (NIHR) in the UK, PPI is the active partnership between patients, the public and researchers in the research process, as opposed to the role of people as 'subjects' of research. PPI is defined as carrying out research 'with' or 'by' people who use services rather than 'to', 'about', or 'for' them [16]. The INVOLVE Organization in the UK <sup>[2]</sup> states that PPI would include contribution in the choice of research topics, assisting in the study design, advising on the research project or in implementing the research, interpretation of results, and dissemination. The PPI evidence base has expanded significantly over the past decade in health sciences, facilitated by Staniszewska and colleagues <sup>[3]</sup> in the development of the Guidance for Reporting Involvement of Patients and Public (GRIPP) checklist, which serves as a framework for reporting and involving patients and the public in research. Nevertheless, the reporting of PPI in published papers related to the QoL of PWA has often been inconsistent or partial. There is little or no information about the context, the process, and the impact of PPI in stroke aphasia research, coupled with limited reporting on the conceptualization or the theoretical underpinning regarding the involvement of PWA as stakeholders.

In the literature the term public and patient 'involvement' is used interchangeably or synonymously with terms such as: Patient engagement, layperson, PPI contributor, peer research, expert by experience, consumer, service user, stakeholders, stakeholder engagement, user involvement, research partners, patient partner, and co-researcher<sup>[2]</sup>. There are different levels of involvement according to the conceptual framework proposed by the Irish Health Research Forum (IHRF). The IHRF framework <sup>[4]</sup> states that patients could be involved in PPI research at various levels starting with (1) providing basic information about their condition, (2) having a consultation role throughout the research process, (3) taking an active role in research planning and decision making, (4) initiating research and being actively involved throughout the process and, finally, (5) having full control of the study and work in partnership with the research team from passive partners to active leading roles. Patient involvement ranges from stakeholders' input, to consultation, to collaboration, or shared leadership <sup>[5][6]</sup>. PPI can be incorporated in ad hoc working groups to develop dissemination strategies or to provide input in an advisory committee or co-researcher capacity <sup>[7]</sup>.

How aphasia and stroke impact the lives of PWA has been studied for many years, and now it is time for PWA themselves to set their own research priorities and explore specific issues that usually do not attract public funding. Research proposals formulated by PWA will be of high-impact value not only in the society of the rehabilitation experts but especially to the stroke survivors' community. Positive effects of studies that consistently include PWA will provide confidence and expectations for PWA to express their needs and get tailored rehabilitation. Personalized and qualitative therapeutic goals will enable rehabilitation specialists to gain more insight into the communication barriers chronic stroke survivors with aphasia face, which reduce their social integration. The American Speech and Hearing Association- Quality of Communication Life Scale<sup>[8]</sup> suggests that "the more positive the personal and environmental factors, the more successful the [person's] communication acts, the better the quality of communication life" (p. 2).

Taking into consideration the perspectives of PWA, as service users, in all phases of the research, is critical to generating findings that will accelerate translation to real-world clinical practice and promote functional interventions and strategies for living successfully with aphasia (activity and participation level: ICF, 2001). According to the Five Good Communication Standards of the Royal College of Speech and Language Therapists <sup>[9]</sup>, the individual risk of having a communication difficulty means PWA are misunderstood and experience failure and exclusion from events, activities, and relationships. Good communication only exists as part of positive everyday relationships, boosting self-esteem and success. Good communication crosses all dimensions of care, support, and enablement. Without good communication PWA struggle to learn, achieve, and make friends, all fundamental for citizenship and central to improving quality of life. Communication quality in PWA is defined based on the following: (1) Involvement with decisions about their care, (2) making choices about daily life activities, (3) creating opportunities to communicate needs and thoughts, (4) to be understood and able to express their wants in relation to their health and well-being, and (5) being treated with respect and dignity <sup>[9]</sup>. PWA should have the opportunity to establish good communication with the scientific society as well.

### **3. Limitations and Future Recommendations**

The variability in the term 'patient involvement' in PWA and the lack of a definition may have restricted the search process as important concepts might have been ignored when determining the search terms. Another limitation is the relatively small number of studies that reveal the involvement of PWA in research, which makes it difficult to profile the engagement of PWA in research studies.

A major challenge in PPI of PWA is the 'approach' of how to put it into practice. There is an absence of standard approaches and frameworks conducting and reporting PPI with PWA, which limits the potential for indexing, knowledge synthesis, and comparative effectiveness to determine best practices. Additionally, this review revealed an inconsistency in the term used by the published studies in involving PWA as research partners. A future recommendation is that researchers who are translating, adapting, and validating pre-established QOL and AIR tools into other languages, involve PWA and their communication partners in their study protocols and as research partners throughout the study using the GRIPP2 reporting checklist<sup>[10]</sup> or any other relevant framework. Future research should focus on the creation of a comprehensive conceptual framework for qualitative participatory approach in aphasia research, which is meaningful to PWA and engages them in research partnership within each research phase. There is a strong need for the creation of such a functional methodological framework based on foundational engagement principles to facilitate patient-centered qualitative research design for people with communication impairments.

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