

PERSONA-SET INTRODUCTION

ABOUT THIS PERSONA-SET

A persona-set is a collection of research-based profiles presenting different kinds of people, their needs, and their everyday lives. They are built from data reflecting real people's experiences, with the intention to help others imagine how different individuals experience everyday life, challenges, and opportunities.

This persona-set captures the stories of children recovering from stroke and their families. This set was developed within BUILD CARE, a multidisciplinary research project exploring how the spaces where these children live, learn, and receive care influence their recovery and quality of life. The research included families in three European countries (Austria, Belgium, and Germany). It gathered insights into experiences of both informal environments, such as homes, neighbourhoods, and schools, and formal care spaces, such as hospitals, clinics, and rehabilitation centres.

To support different ways of using the persona-set, we have prepared two printable formats: an A4 version that is easy to print at home, and an A3 version well-suited for workshops and group discussions. Both are ready for you to download and use.

WHO IS THIS PERSONA-SET FOR?

Architects, designers, healthcare professionals – the personas can help you better understand the everyday lives of children affected by stroke, including those who make a full recovery and those living with lasting disabilities. They highlight both the challenges children and their families face in the built environment and the creative strategies they adopt to cope. The personas capture not just the physical needs, but also the cognitive and emotional aspects of life after stroke. By sharing these insights, the personas can inspire creating more inclusive, supportive, and enabling environments.

Families affected by childhood stroke – the personas may be just as valuable to you. Many of you will recognise pieces of your own story in these personas, which may help to feel seen and understood. They may also open up conversations about what kinds of spaces and features in the built environment really make a difference in everyday life. As you shape care environments in everyday ways and through formal decisions during the design process, this resource can help you imagine possibilities beyond your own personal experiences.

In this way, the personas become a shared reference point connecting families, practitioners, and researchers in building a common understanding of what it can mean to live with the lasting effects of childhood stroke.

WHAT THE PERSONAS OFFER



Each persona begins with **background information** about the child and their caregivers, including when the stroke happened and how it has affected them.



The personas are brought to life through **scenarios** showing how a child and their families use, experience and modify everyday spaces. The scenarios illustrate how they experience different environments, highlighting barriers, opportunities, and moments where thoughtful design could make a difference. A simple gradient, shown as different lines under the relevant text, helps readers quickly understand how each environment or activity affects the child's experience and whether a situation is impossible to overcome, only possible with help, possible with the help of tactics, supports their independence or is experienced as enabling.




Every persona includes a **care map** – a spatial overview of important places in the child's life. It also shows the distances between these places, helping to illustrate the journeys that shape their daily routines. These distances and frequencies are illustrative and will differ by home location and care needs, resulting in a map unique to each family.



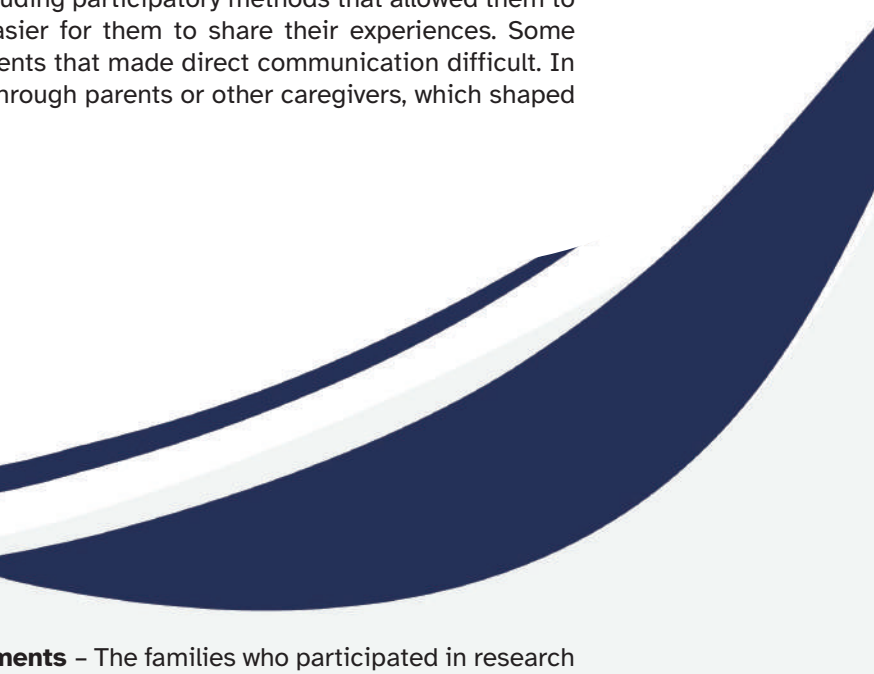
Each persona includes examples of additional **stroke-related costs** that families may encounter, such as one-time expenses (for example, a grab bar or adaptive kitchen tools), and indicates what expenses were reimbursed by health insurance.

Household incomes shown in the personas are illustrative gross amounts. Travel-related costs, such as fuel, bus or train tickets and taxis, and the purchase or adaptation of a vehicle, were not included in this study.



Data sources shaping the personas – The persona development was based on interviews with 30 families affected by childhood stroke, cognitive data from standardised neuropsychological testing with 15 children, and findings from an online survey exploring the well-being and socio-economic impacts on these families completed by over 100 families across the three participating countries.

Foregrounding children's voices – A core value of the project was to involve children as active participants, not just as subjects of observation. The research team developed creative and age-appropriate ways to hear children's voices, including participatory methods that allowed them to draw, play or take photographs, which made it easier for them to share their experiences. Some children, however, were very young or had impairments that made direct communication difficult. In these cases, their perspectives were investigated through parents or other caregivers, which shaped the kinds of insights that could be gathered.



Diversity of participants' stroke-related impairments – The families who participated in research reflected a broad variety of impairments, which is characteristic of the diversity seen after childhood stroke. This variety is represented in the persona-set and helps illustrate many different needs and abilities. That said, the group did not include children with the most severe physical disabilities, such as those with extremely limited mobility or requiring intensive daily care, or those with profound communication impairments. While the personas focus on how stroke interacts with the built environment, co-occurring conditions such as autism can be just as influential in everyday life as stroke-related impairments. Because recruitment across countries was stroke-oriented, this resource remains primarily stroke-focused, and readers may wish to consult condition-specific research for further guidance. As a result, some spatial, care-related, or communication challenges may not be fully represented.

Diversity of families' characteristics – Most of the families presented in the personas have a higher socio-economic status, largely due to the recruitment methods and participation requirements. As a result, the experiences of families with fewer resources may not be fully represented. It is also important to note that the families who participated in this project were highly involved in supporting their child and willing to participate in research. Families who may be less engaged or face greater challenges in accessing support are not as well represented in this persona-set. However, information from an online survey was used to ensure the sample is representative of the broader population in terms of age, gender, family structure, and economic situation. This helps make the personas more accurate and realistic.

Including wider family perspectives – The project placed strong emphasis on the family as a whole, and where possible, included the voices of siblings, grandparents, and other relatives. These perspectives can be particularly insightful, as these family members often contribute meaningfully to care and daily routines. Nevertheless, their experiences are less prominent than those of primary caregivers, meaning some aspects of their support roles may be underrepresented.

Other factors shaping lived experience – While the project focused primarily on experiences related to childhood stroke, factors such as migration background, ethnicity, language barriers, or co existing disabilities can also shape how families interact with care environments and services. These aspects were not a central focus of the study, but they remain important for understanding the full range of lived experiences.

While no set of personas can capture every perspective, these personas provide a strong foundation to understand and support families better. Recognising where perspectives may be less included is an invitation to keep listening, learning, and expanding our view in future research efforts.

ACKNOWLEDGMENTS

We are deeply grateful to the children and families who shared their stories and experiences, making this persona-set possible.

The BUILD CARE team included Andrea Jelić, Ann Heylighen, Anna Franziska Kalhorn, Anna Hella Borsch, Anna-Theresa Renner, Anne-Sophie Schoss, Birgit Moser, Charlotte Rathjen, Els Ortibus, Gesine Marquardt, Johanna Baldassari, Lena Fuchs, Lisa Bartha-Doering, Maja Kevdžija (Project Coordinator), Magdalena Muszynska-Spielauer, Marion Göll, Mie-Jef Descheemaeker, Piet Tutenel, Pleuntje Jellema, Ruth Heying, Sophie Mandl, and Viktoria Kurstak. Each member made meaningful contributions to the project, bringing their expertise, dedication, and creativity to every stage of the work. We would like to express our special thanks to our colleagues: to Pleuntje Jellema for developing the care maps and the persona-set layout, and to Lena Fuchs for creating the drawings that illustrate the scenarios in the persona-set.

We also thank our collaborators SCHAKI e.V., Stiftung Deutsche Schlaganfall-Hilfe, and Rarity United, as well as the BUILD CARE advisory board: patient representatives, architects, healthcare professionals, interior designers, and other experts, for their valuable insights and guidance.

GLOSSARY OF TERMS

This glossary explains key words and concepts used throughout the persona-set. It is designed to help everyone, whether families, designers, or healthcare professionals, understand the language and ideas that shape these personas. This glossary does not cover every term but highlights selected medical, country-specific, and other key concepts (for example, formal and informal care environments) to help make the persona set clear and accessible for everyone, regardless of their background or familiarity with these concepts. By sharing clear definitions, we hope to make the personas easy to explore and use in supporting children affected by stroke and their families.

Attentional deficits: Difficulty focusing, sustaining attention, or filtering distractions.

Cognitive impairment: Difficulties with thinking, memory, attention, language, or problem-solving due to brain injury or other causes.

Dyspraxia: A condition affecting physical coordination, often making tasks like writing, dressing, or using tools more difficult.

Formal care environments: Institutional settings like hospitals, rehabilitation clinics, and outpatient clinics where professional medical or therapeutic care is delivered.

Hemiparesis: Weakness or partial paralysis on one side of the body often caused by stroke. It can be arm-dominant (more pronounced in the arm and hand), leg-dominant (more pronounced in the leg and foot), or affect both equally with varying severity.

Informal care environments: Everyday settings such as the home, school, and neighbourhood where care occurs outside the formal healthcare system.

Inclusive schooling: Educational settings that accommodate children with and without disabilities.

Motor skills: The ability to perform movements, including gross motor skills—large movements like walking or jumping, and fine motor skills—precise movements like using fingers or handling small objects.

Neuroplasticity: Brain's ability to change, adapt, and reorganize itself by forming new neural connections throughout life.

Orthosis: A device, such as a brace, that supports weakened muscles or joints, often worn on arms or legs to assist with walking or movement.

Paresis: Partial loss of voluntary movement or muscle strength.

Seizures / Epilepsy: Sudden bursts of abnormal brain activity that may cause convulsions, confusion, or sensory disturbances. Some children in the study took anti-epileptic medication.

Sensory-reduced space: A quiet, low-stimulation environment where children can retreat from noise or visual overload to recover focus and calmness.

Snoezel garden: A calming, multi-sensory outdoor space designed to help children relax, self-regulate, and engage their senses.

Social Paediatric Centre: A specialised outpatient clinic (in Germany) that provides interdisciplinary diagnosis, consultation, and therapy for children and adolescents with developmental delays, chronic conditions, or disabilities.

Visuoperceptive deficits: Challenges in processing and understanding visual information, affecting activities like reading or navigating space. The ability to perceive things like shapes, objects and faces may be affected; it may be hard to distinguish an object from what is in the background; also detecting and understanding motion, judging distances, navigating spaces and understanding spatial relationships may be experienced as difficult.

Visual memory deficits: Difficulties in remembering visual information, such as the location of objects (e.g., keys), routes, or faces.



BUILDING SUPPORT FOR CHILDREN AND FAMILIES AFFECTED BY STROKE

This persona-set was made in the context of the BUILD CARE research project which received funding from the European Union's Horizon 2020 research and innovation programme under the European Joint Programme on Rare Diseases (N° 825575) and the national/regional funding partner organisations: FWF (Austria), BMBF (Germany) and FWO (Flanders, Belgium). Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or national/regional funding agencies. Neither the European Union nor the granting authorities can be held responsible for them.

Project period: 2022 - 2025

www.buildcare-project.eu

PROJECT PARTNERS



TECHNISCHE
UNIVERSITÄT
WIEN



Technische
Universität
Dresden



MEDIZINISCHE
UNIVERSITÄT WIEN