

CO-CREATING PERSONAS FOR HIV AND AIDS HEALTH LITERACY: INSIGHTS FROM THE PORTUGUESE PROJECT VIHVER

Cristina Vaz de Almeida

Sociedade Portuguesa de Literacia em Saúde, Oeiras, Portugal/Centro de Administração e Políticas Públicas, Instituto Superior de Ciências Sociais e Políticas, Universidade de Lisboa, Lisbon, Portugal
Conceptualisation, data curation, formal analysis, investigation, methodology, software, resources, supervision, validation, visualisation, writing – original draft, writing – review & editing

Ana Correia

Grupo de Ativistas em Tratamentos, Lisbon, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Andreia Pinto Ferreira

Associação Portuguesa para a Prevenção e Desafio à SIDA, Cascais, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Catarina Esteves Santos

Hospital de Cascais, Cascais, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Cristina Mora

Associação Humanitária de Saúde e Apoio Social, Rio de Mouro, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Cristina Sousa

Associação Abraço, Lisbon, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Diva Trigo

Faculdade de Medicina, Universidade de Lisboa, Lisbon, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Maria Isabel Casella

Hospital de São Bernardo, Setúbal, Portugal/Grupo de Ativistas em Tratamentos, Setúbal, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Josefina Mendez Vazquez

Associação Abraço, Lisbon, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Maria Eugénia Saraiva

Liga Portuguesa Contra a SIDA, Lisbon, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Patrícia Pacheco

Hospital Professor Doutor Fernando Fonseca, Amadora, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Ricardo Fernandes

Grupo de Ativistas em Tratamentos, Lisbon, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Rita Pires

Associação de Intervenção Comunitária, Desenvolvimento Social e de Saúde, Amadora, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Sílvia Ouakinin

Liga Portuguesa Contra a SIDA, Lisbon, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Vitalina Silva

Associação de Intervenção Comunitária, Desenvolvimento Social e de Saúde, Amadora, Portugal
Conceptualisation, data curation, validation, writing – review & editing

Célia Belim

Sociedade Portuguesa de Literacia em Saúde, Oeiras, Portugal/Centro de Administração e Políticas Públicas, Instituto Superior de Ciências Sociais e Políticas, Universidade de Lisboa, Lisbon, Portugal
Conceptualisation, data curation, formal analysis, investigation, methodology, software, resources, supervision, validation, visualisation, writing – original draft, writing – review & editing

ABSTRACT

The challenges posed by human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) are predominantly addressed from a biomedical standpoint. However, limited research explores the involvement of key community-based organisations that support individuals living with HIV and AIDS. This study examines the Portuguese project *VIHVER*, which fosters partnerships between representatives of community-based organisations and healthcare professionals through participatory collaboration and the co-creation of health promotion content. The aim is to map the co-creation process of personas used in communication campaigns developed by Portuguese associations engaged in *VIHVER* and to analyse these personas from a linguistic perspective. A qualitative methodology was employed, combining co-creation within the frameworks of community-based participatory research and integrated knowledge translation alongside participant observation and semiological analysis. The study transparently outlines the development of six personas designed to promote health literacy regarding HIV and AIDS, thereby addressing a gap in existing research. The analysis of verbal, visual, and graphic language highlights their significance in shaping effective and representative personas. Findings indicate that the grassroots co-creation process undertaken by the six associations constitutes a pluralistic, innovative, and practical model. It aligns with core principles of health literacy and offers potential for replication, broader applicability, and mutual benefit across stakeholders.

KEYWORDS

HIV, AIDS, persona, health literacy, co-creation

QUEM SEMEIA COCRIAÇÃO DE PERSONAS LIGADAS AO VIH E SIDA COLHE LITERACIA EM SAÚDE: O PROJETO PORTUGUÊS VIHVER

RESUMO

A problemática do vírus da imunodeficiência humana (VIH) e síndrome de imunodeficiência adquirida (SIDA) está geralmente confinada a uma perspetiva biomédica. São poucos os

casos de investigação sobre a participação das entidades com peso na intervenção comunitária, como as associações de cariz comunitário que apoiam pessoas que vivem com VIH e SIDA. O estudo apresentado foca-se no projeto português *VIHVER*, que investiu na criação de parcerias entre os representantes destas associações de cariz comunitário e profissionais de saúde, numa simbiose participativa e de cocriação de conteúdos promocionais de saúde. O presente estudo visa mapear o processo de cocriação de personas usadas nas campanhas de comunicação das associações portuguesas integradas no projeto *VIHVER* e caracterizá-las sob a perspetiva da linguagem. Nesse sentido, usa-se o método qualitativo, assente na cocriação enquanto processo que integra investigação participativa baseada na comunidade e tradução integrada de conhecimentos, na observação participante e na análise semiológica. Os resultados detalham, de forma transparente, o processo de cocriação de seis personas para campanhas de literacia em saúde sobre VIH e SIDA, colmatando uma lacuna na investigação. As escolhas de linguagem verbal, icónica e plástica mostram o seu valor para a caracterização competente das personas. Conclui-se que o processo de cocriação desenvolvido desde a sua raiz pelas seis associações é uma experiência plural e altamente representativa, inovadora, utilitária, orientativa, inspirada nos princípios da literacia em saúde e com potencial de replicação, caráter transversal dos dados e ganhos para todos os envolvidos.

PALAVRAS-CHAVE

VIH, SIDA, persona, literacia em saúde, cocriação

1. INTRODUCTION

Although the benefits of co-creation have been well documented, research into its application within health services remains relatively recent (Osei-Frimpong et al., 2018; Zhang et al., 2015). The present study seeks to address this ongoing gap in the literature. In parallel with the promise of co-creation, the use of personas has shown practical and theoretical merit. Widely employed in human-centred and problem-oriented design approaches, personas are increasingly being integrated into health-related interventions (e.g., Wray et al., 2019). However, limited research has explored the incorporation of this tool into health messaging on online social media or how it may be shaped by formative research and evaluation (Massey et al., 2021). Furthermore, the process of designing personas is often marked by a lack of transparency and conceptual clarity (Galliford et al., 2022).

The human immunodeficiency virus (HIV) is a significant global public health issue which has claimed 42.3 million lives and continues to be transmitted in all countries worldwide (World Health Organization, 2024a). According to 2017 data, Portugal ranks as the second country in the European Union (EU) with the highest number of deaths from acquired immunodeficiency syndrome (AIDS; European Centre for Disease Prevention and Control & WHO Regional Office for Europe, 2018). It also leads the EU in new infections and HIV/AIDS rates per 100,000 inhabitants, surpassed only by France and Germany. As a case study, Portugal provides a relevant comparison with other European countries, given that it continues to report higher rates of new HIV and AIDS diagnoses than the EU average (Direção-Geral da Saúde & Instituto Nacional de Saúde Doutor Ricardo Jorge, 2024). Moreover, the country faces a particular challenge related to the connection between new AIDS cases and migrant populations. In 2023, new AIDS diagnoses were predominantly

among individuals born outside Portugal (51.2%), and the majority of paediatric cases in the past decade were found in children born outside the country (53.7%).

Co-creation and personas add value to health literacy strategies on HIV and AIDS by exploring language and communication. In March 2025, a Boolean search was conducted in the EBSCO (<https://www.ebsco.com/>) academic database, described as “a leading provider of research databases”, using the keywords “co-creation or cocreation” AND “persona” AND “HIV/AIDS” and the filter “peer-reviewed”, with no restrictions on language or publication date. This search returned no results, thereby confirming the scarcity of studies addressing the intersection of these topics.

Linking the co-creation of personas with the commitment to address the real needs of people living with HIV (PLHIV) and their caregivers, the *VIHVER* project is a collaborative initiative involving a participating pharmaceutical company — anonymised for ethical reasons, self-protection, and to guarantee the integrity of the scientific study — along with health professionals and various associations: Portuguese Association for the Prevention and Challenge of AIDS (SER+), Portuguese Activist Group on Treatments (GAT), Portuguese League Against AIDS (LPCS), Association for Community Intervention, Social Development, and Health (AJPAS), Humanitarian Association for Health and Social Support (AHSeAS), and Associação Abraço. This study also seeks to address the need, highlighted by Stock et al. (2021), for further research that articulates and documents the key factors contributing to the success of co-creation processes.

Based on the scenario described above, this article aims to (a) map the process of co-creating personas used in the communication campaigns of the Portuguese associations participating in the *VIHVER* project and (b) characterise, from a linguistic perspective, the personas used in the campaigns of these associations.

This study is relevant to communication sciences because it examines communication principles and decisions (e.g., the persona creation process, linguistic and visual resources) that can enhance health literacy related to HIV and AIDS while expanding the understanding of the co-creation of health messages — a critical aspect of the effectiveness of health literacy campaigns (e.g., Muscat et al., 2023). Traditionally, communication about HIV and AIDS has been dominated by a biomedical perspective, often overlooking the active role of affected communities. This study contributes to bridging this gap by documenting the involvement of community associations in the development of campaigns, emphasising the importance of language and visual representations in effective communication. Stakeholder engagement in the creation of campaigns not only improves the representativeness of messages, breaking down cultural barriers and social stigma, but also promotes greater acceptance and adherence to health recommendations (Lambert & Loiselle, 2007; van den Heerik et al., 2016). Additionally, this study underscores the significance of visual communication in health campaigns, a topic that has been widely explored in communication sciences. The way information is encoded in campaigns and interpreted by the audience (Hall, 1980) has a direct influence on their success and ability to generate social impact (Tulsiani et al., 2022; Wakefield et al., 2010).

2. CO-CREATION AS A CO-BENEFIT FOR STAKEHOLDERS: UNITY IS STRENGTH

Co-creation refers to a collaborative approach to creative problem-solving among diverse stakeholders, engaged across all stages of an initiative — from problem identification and solution generation to implementation and evaluation (Vargas et al., 2023). It also encompasses any act of collective creativity that draws on a broad array of methods and processes (Stock et al., 2021) or a resource integration process involving actors within a service ecosystem (Frow et al., 2016). In health promotion, co-creation may be understood not only as a means but also as an end in itself — “the process of enabling people to increase control over and to improve their health” (Nutbeam, 1998, p. 349). Originally rooted in management science and software design, the concept of “co-creation” emphasised achieving synergistic effects through user participation in design processes (Stock et al., 2021). In community and health contexts, co-creation is frequently described as a participatory research model (Greenhalgh et al., 2016) or as a process that intersects with community-based participatory research and “integrated knowledge translation” (Jull et al., 2017, p. 2). *Integrated knowledge translation* is a collaborative and contextualised approach to producing and applying knowledge aimed at addressing the needs of knowledge users in health systems. It relies on the active involvement of these users throughout the research process, ensuring that research structures and methods are sensitive to context and oriented towards implementation. More recently, the concept of “co-creation” has been increasingly associated with terms such as “empowerment”, “participation”, “engagement”, and “citizenship”, reflecting a growing commitment to involving citizens in decision-making processes (Darlington & Masson, 2021).

Co-creation occurs when value propositions attract actors to share their resources through collaborative activities and interactions, referred to as “co-creation practices” (Frow et al., 2016). A typology of co-creation practices that shape a dynamic healthcare service ecosystem can be outlined (Frow et al., 2016): (a) practices that endow actors with social capital; (b) practices that provide an ecosystem with a shared language, symbols, signs, and stories; (c) practices that shape an actor’s mental model; (d) practices that impact the ecosystem, created or constrained by the physical structures and institutions that form their contexts; (e) practices that shape existing value propositions or inspire new ones; (f) practices that impact access to resources within an ecosystem; (g) practices that forge new relationships, generating interactive and/or experiential opportunities; and (h) practices that are intentionally co-destructive creating imbalance within the ecosystem (e.g., when online groups advocate withholding children from inoculation, increasing the risk of disease proliferation and disrupting local communities).

Based on a content analysis of existing studies involving co-creation, Pearce et al. (2020) identified four phases of collaboration in co-creation research: (a) the generation of an idea (co-ideation); (b) the design of the programme or policy and the research methods (co-design); (c) the implementation of the programme or policy in line with the agreed research methods (co-implementation); and (d) the collection, analysis, and interpretation of data (co-evaluation).

With regard to the use of co-creation in HIV and AIDS initiatives, one study aimed to collaborate with key stakeholders to reach a consensus regarding the predominant

barriers preventing the uptake of HIV testing services by men in Rwanda and co-create an acceptable educational program to improve the knowledge of HIV self-testing among this target audience (Dzinamarira et al., 2020). The nominal group technique method was employed to conduct a highly structured group discussion. Participants were recruited using the snowball sampling technique and selected based on the researchers' assessment that they would contribute valuable insights regarding the study's focus. Four representatives of the target population (the potential users of HIV self-testing) and eight individuals likely to have expert knowledge of HIV services, men's health services, HIV self-testing and health promotion in Kigali, Rwanda, were recruited. The barriers identified included fear of the aftermath of an HIV-positive result, misconceptions regarding masculinity, self-stigma, fear of stigma and discrimination, and misinformation regarding HIV prevention methods. The educational programme developed addressed the benefits of knowing one's HIV status, current HIV self-testing distribution methods, and HIV care and treatment services. Further studies are needed to evaluate the programme's effectiveness.

3. PERSONAS AND LANGUAGE USE

The literature and health communication practice increasingly argue that a “one-size-fits-all” approach to designing digital health is not optimal and that personalisation is essential to achieve targeted outcomes (Galliford et al., 2022). Yet, most digital health practitioners struggle to identify which design aspects require personalisation (Galliford et al., 2022). In this context, personas are commonly used to communicate patient needs, supporting optimised health outcomes through mechanisms of identification and projection. However, there is often a lack of reproducible clarity on the development process and few attempts to assess their accuracy against the targeted population (Galliford et al., 2022).

Personas are based on real-life typologies of people that can be used to create characters and messages related to health (Massey et al., 2021). They incorporate details such as demographic information, behaviours, goals, and professions and are intended to represent archetypal patients (Giunti et al., 2018). Personas can also serve to communicate key motivations, concerns, and interests (Maguire, 2001). They are endowed with specific characteristics, reflecting the idea that the more specific the persona, the more effective they are as a design tool (Henry, 2007; Neate et al., 2019). Their integration into narratives has been shown to enhance remembering and organising detailed data about users (Neate et al., 2019).

The development of personas is data-driven and typically involves several phases of formative research and evaluation. Generally, constructing personas entails conducting interviews, making observations, and immersing oneself in the context that informs the creation of characters based on real archetypes. Drawing on data, researchers use verbal language to describe the type of person the persona represents and apply visual language principles to construct their visual identity (e.g., Belim, 2024). Personas vary in length — ranging from a brief paragraph to a full page — and usually include an image, which might be a sketch, a cut-out photograph from a magazine, or a stock image (Henry, 2007).

Regarding language use, Bhattacharyya et al. (2019) highlight that a persona is often accompanied by a “user story”: a narrative describing the actions and decisions of a user in a particular context.

Focusing on the construction of personas related to HIV and AIDS, the study by Wray et al. (2019) describes a user-centred and interaction design research approach to inform the development of a tablet-optimised web application. This application aimed to help heavy-drinking gay and bisexual men reduce their risk for HIV when they seek HIV testing. Focus groups were conducted with subject matter experts ($N = 10$) and intended users ($N = 25$). Within the expert group, HIV test counsellors were recruited to provide an understanding of the priorities and challenges of post-test counselling. The experts emphasised the importance of putting patients at ease and suggested that interventions should prioritise identifying personal risks and provide options for change.

In focus groups with intended users, participants created detailed, personalised models of two “typical” users of the proposed app (“personas”) that could be used to guide design decisions. Two personas were created: Terry and Joel. “Terry” is a 19-year-old gay man who is seeking HIV testing because of a possible recent exposure. Participants described Terry as generally young and healthy and that he was enjoying the new freedoms and increased attention from other guys. As a result, they said, he may see himself as invincible. Terry most often met guys using smartphone apps or when “clubbing” with friends, which frequently made practising safe sex difficult. Participants mentioned that Terry may feel conflicted about his choices as he tries to understand his identity. Terry was also not particularly well-connected with the gay community where he lives, instead seeking advice and information from popular online personalities. Through these sources and his few young friends, Terry mostly associates HIV with older gay men. “Joel” is a 55-year-old single gay man who seeks testing as part of his normal routine, regardless of risk incidents. Participants imagined that Joel is more aware of the risks posed by HIV because he is older and experienced the effects of AIDS on his friends first-hand. Yet, they noted that Joel may still struggle to make safe decisions because of a poor self-image. Participants pictured Joel attempting to meet guys primarily in gay bars and clubs, often drinking to intoxication because he believes he is more charming (and less boring) when he has been drinking, thus encouraging him to drink more in the hope of meeting someone. Joel may make unsafe decisions because he is too intoxicated to care. However, his fatalistic beliefs about HIV may contribute to this behaviour.

Terry was chosen as the primary persona because his perspective represents a common scenario for many patients who present for testing. Both personas underscored the importance of creating a comfortable user experience and offering content that is relevant across the various stages of behavioural change.

4. THE ROLE OF CO-CREATION AMONG HEALTH ORGANISATIONS, PROFESSIONALS AND PATIENTS AND THE USE OF PERSONAS IN ADVANCING HEALTH LITERACY

One of the most widely recognised definitions of *health literacy* is that adopted by the World Health Organization (WHO; 2024b): being able to access, understand, appraise

and use information and services in ways that promote and maintain good health and well-being. This domain of literacy is grounded in the representation of personal knowledge and competencies that accumulate through daily activities, social interactions and across generations (World Health Organization, 2024b). In an effort to systematise and update the discussion on the concept of “health literacy”, we draw on the literature review conducted by Liu et al. (2020). Based on an analysis of 34 original studies, the researchers found that health literacy is commonly conceptualised as a set of knowledge, a set of skills or a hierarchy of functions (functional-interactive-critical). They also observed that the construct of health literacy covers three broad elements: (a) knowledge of health, healthcare and health systems; (b) processing and using information in various formats in relation to health and healthcare; and (c) ability to maintain health through self-management and working in partnerships with health providers. The authors conclude that health literacy has been commonly interpreted as an ability to use general literacy skills (reading, writing, numeracy, listening and speaking) to obtain, understand, appraise, synthesise, communicate and apply health-related information.

Health literacy plays a key role in several ways, including enhancing individuals’ understanding of health-related concepts and strengthening their ability to take responsibility for their health. It also affects treatment adherence, the frequency of healthcare utilisation, hospitalisation rates, and the associated financial burden (e.g., Coughlin et al., 2020; Shahid et al., 2022). The literature suggests that people with higher levels of health literacy tend to make better-informed health decisions, are more likely to follow treatment plans and use health resources more efficiently (e.g., Miller, 2016; Santos et al., 2017). However, the relationship between health literacy and effective decision-making is complex. Possessing health literacy skills does not necessarily translate into the ability to apply them in practice (e.g., Heijmans & Rademakers, 2018), and “health literacy” and “patient activation” are separate concepts (Hibbard, 2017). Improved health literacy does not automatically result in better health decisions, as factors such as decision-making ability and contextual influences also play significant roles (e.g., Essink-Bot et al., 2016; Rüegg, 2022). Studies show that interventions can enhance both health literacy and health behaviours (Walters et al., 2020), but improvements in one area do not automatically lead to changes in the other (Hibbard, 2017). Effective strategies should, therefore, target both, as each can make independent contributions to health outcomes (Hibbard, 2017; Long & Gambling, 2011).

Co-creation in health promotion aims to improve the lives of those who are subjects of research by empowering them to contribute to the research process and outcomes. This participatory approach helps advocate for transformative initiatives and changes in public policies that address their health needs (Stock et al., 2021). Co-creation can facilitate the development of effective solutions for underserved patients with multi-morbidity and less than optimal health literacy who experience major obstacles in navigating the health system. For instance, the Canadian study documented by Loignon et al. (2018) integrated participatory health processes and action research to co-create, with patients and community members impacted by health literacy, practical recommendations or solutions

for facilitating navigation of the healthcare system and health literacy among underserved patients or Aboriginal people with low literacy. The ideas that evolved from engaging with patients/individuals in exploring what would improve their visits with a healthcare provider have led to one co-creation, namely, the development of a wallet card and an online app so that patients/individuals can better navigate the healthcare system and more optimally engage in self-care.

At the organisational level, the extent of interaction and the degree of patient involvement with healthcare professionals are closely linked to opportunities for co-creation (Kim, 2019). When co-creation is grounded in assertive, clear, and positive communication between the parties involved (Vaz de Almeida, 2021, 2023a, 2023b; Vaz de Almeida & Fragoeiro, 2023), it fosters the sharing of common values, supports the attainment of organisational goals, enhances patients' therapeutic outcomes, and increases both their respect for the healthcare organisation and the value they attribute to it (Salavati et al., 2022).

Regarding the contribution of personas to health literacy and health, studies have shown that they can (a) enhance stakeholder engagement by providing detailed insights into patient needs (Bhattacharyya et al., 2019), (b) help make problems and solutions more tangible and relatable (Bhattacharyya et al., 2019), and (c) increase patient satisfaction with tailored health interventions, particularly when disease-specific personas are used, thereby promoting greater patient engagement and activation (Serio et al., 2015).

5. STATISTICAL OVERVIEW OF HIV AND AIDS

HIV remains a major global public health concern (World Health Organization, 2024a). Alarmingly, some countries that had previously recorded a decline in new infections are now witnessing a resurgence, raising renewed concern.

In Portugal, 924 new cases of HIV infection were diagnosed in 2023, corresponding to a rate of 8.7 cases per 100,000 inhabitants (Direção-Geral da Saúde & Instituto Nacional de Saúde Doutor Ricardo Jorge, 2024). In the same year, 129 new cases of AIDS and 111 deaths related to HIV or AIDS were reported. Cumulatively, from 1983 to 2023, Portugal recorded 68,627 cases of HIV infection, including 23,955 in the AIDS stage, and 15,918 deaths (Direção-Geral da Saúde & Instituto Nacional de Saúde Doutor Ricardo Jorge, 2024, 2024).

Globally, an estimated 39 million people were living with HIV by the end of 2022, with two-thirds (25.6 million) residing in the WHO African region (World Health Organization, 2024a). That year, 630,000 people died from HIV-related causes, and 1.3 million individuals became newly infected (World Health Organization, 2024a).

While there is currently no cure for HIV infection, access to effective prevention, diagnosis, treatment and care has transformed it into a manageable chronic condition, enabling many PLHIV to lead longer and healthier lives (World Health Organization, 2024a). The WHO, the Global Fund, and UNAIDS have each developed global HIV strategies aligned with target 3.3 of the United Nations sustainable development goals, which aim to end the HIV epidemic by 2030.

6. METHOD AND MATERIAL

A qualitative methodological approach was adopted for this study. To achieve the first objective, participant observation focused on data collection, alongside co-creation practices that combine community-based participatory research and “integrated knowledge translation” (Jull et al., 2017, p. 1), were employed. A semiological analysis was used to address the second objective, focusing on data interpretation.

The co-creation process involved collaboration between the associations — each of which selected a healthcare professional from a hospital to which they typically refer their users — and the participating pharmaceutical company. Together, and by optimising their synergies, they defined the persona and jointly made all campaign-related decisions. The selection of healthcare professionals reflected the functional structure of each association (which refers its users to specific hospitals). Each association operates within a particular geographical area with its distinct social fabric and corresponding medical and/or social needs, all of which inform the development of the persona. The pharmaceutical company facilitated the coordination of stakeholder meetings and was responsible for designing the campaign platform (<https://www.vihver.pt>). The initiative to develop a co-creation project on health literacy regarding HIV and AIDS originated with the pharmaceutical company, which reached out to the associations with an open invitation to participate in a project aimed at raising awareness of the disease. The associations were granted full freedom to shape the campaign in alignment with their needs and expectations. All participants expressed strong motivation to take part in the initiative, as they felt heard, included, and empowered to address a concrete and pressing health need within the communities they serve. The co-creation process — specifically the development of personas, excluding the phase dedicated to evaluating their persuasive impact — took place between April and December 2022.

Participant observation is a data collection technique that connects the researcher to lived human experience, enabling the discovery — through immersion and participation — of the *hows* and *whys* behind behaviours and decisions within a specific context (in this case, related to the co-creation of personas to promote health literacy about HIV and AIDS). This technique required the systematisation and organisation of an inherently fluid process. According to Guest et al. (2013), participant observation involves acting both as a participant within a social environment and as a researcher — taking notes, analysing documents and images, and asking questions to uncover the meaning behind practices (such as the profiles and behaviours of people living with HIV) and decisions (such as those related to the co-creation of personas connected to HIV and AIDS).

In order to address the second objective, semiotic analysis was employed. The *corpus* in this study consists of the final version of the personas co-created by the associations involved in the VIHVER project (Table 1). This method focuses on uncovering the deeper meanings of messages, aiming to identify underlying structures, latent content, and the processes of meaning-making through signs, codes, and binary oppositions (Neuendorf, 2017). The analytical instrument used was the denotation–connotation framework. Within this framework, attention was paid to both verbal and visual

elements: words and linguistic expressions in the written text, as well as icons — particularly colour and shape — in the images. The analysis unfolded across two levels: denotative analysis, which examines the objective component by identifying signifiers (e.g., colour, shape), and connotative analysis, which requires interpretation based on the articulation of theoretical and cultural knowledge (Barthes, 1977).

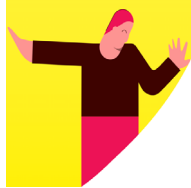


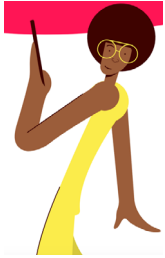


ASSOCIATION	DESCRIPTION OF THE PERSONA	GRAPHIC VERSION OF THE PERSONA
PORTUGUESE ASSOCIATION FOR THE PREVENTION AND CHALLENGE OF AIDS	<p>“I am not the virus”</p> <p>Hello, I am 33 years old. I am HIV positive with an undetectable viral load, which means I cannot transmit the virus to others. I like who I am, and I am not ashamed of being HIV-positive. I want people to see me for who I am, as more than the virus. I want to have a child. I want to grow old with the person I love, who loves me back. Living with HIV does not prevent me from achieving any of this.</p>	
PORTUGUESE ACTIVIST GROUP ON TREATMENTS	<p>“Difficulties with medication”</p> <p>Hello, my name is Carlos, and I am 50 years old. I was diagnosed two years ago, and I am currently under medical care and on treatment. However, I often forget to take my medication on time. Because I feel fine, I don't give it much thought.</p>	
PORTUGUESE LEAGUE AGAINST AIDS	<p>“Mental health”</p> <p>Hello, my name is Joaquim, and I am 57 years old. I take daily medication for HIV, my viral load is undetectable, and I cannot transmit the virus. I know this, but my family and some of my friends do not, which frightens me, saddens me, and often makes me isolate myself.</p>	
ASSOCIATION FOR COMMUNITY INTERVENTION, SOCIAL DEVELOPMENT, AND HEALTH	<p>“Reducing risk and promoting screening”</p> <p>Hello! My name is Jorge, and I am 43 years old. I never imagined I would be living with HIV today. I have always enjoyed being with different women, but I never thought I could get infected. Today, I encourage my children and friends to protect themselves by using condoms. I want them to have access to more information than I did when I was growing up in Guinea-Bissau. I advise anyone who has had risky contact to get tested for HIV. Knowing your diagnosis is important so you can start treatment; that way, you won't have symptoms and won't pass the virus on to anyone else.</p>	
HUMANITARIAN ASSOCIATION FOR HEALTH AND SOCIAL SUPPORT	<p>“Having a normal life”</p> <p>My name is Aua, I am 37 years old, from Guinea, and I live with HIV. I have two children and work two jobs to support my family. I go to great lengths to hide my HIV status out of fear — of losing my job, being excluded from society, and especially from my own community.</p>	
ASSOCIAÇÃO ABRAÇO	<p>“Helping those who help”</p> <p>Hello! My name is Hugo, and I am 70 years old. I live with my 40-year-old son, Simão, who has HIV and is entirely dependent on me. I spend my days caring for Simão. I feel exhausted and lonely, with no time left to care for myself.</p>	

Table 1. Descriptions and graphic representations of the personas co-created by the associations involved in the VIHVER project

7. ETHICAL CONSIDERATIONS

This study adopted a rigorous ethical framework to ensure scientific integrity, impartiality of results, and transparency throughout the research process. The collaboration with the pharmaceutical company was explicitly disclosed, and safeguards were implemented to ensure that there was no undue influence on the study's findings. International guidelines were followed, including those of the International Committee of Medical Journal Editors (2019), which recommend full transparency regarding private sector involvement. The methodological and scientific independence of the study was safeguarded: the pharmaceutical company acted solely as a facilitator without influencing the findings, which were grounded in empirical reality rather than commercial interests. Ethics were also upheld in the dissemination of results, avoiding any promotion of the company or its products, prioritising public interest, and promoting health literacy as the study's guiding principle. Equitable participation among stakeholders was ensured, and principles of co-authorship and balanced collaboration were respected, avoiding any single actor exerting dominance. All partners retained autonomy in defining personas and campaign elements, with the needs of patients and communities consistently placed above commercial considerations.

8. FINDINGS

The results are presented according to the two specific objectives of the study.

8.1. CO-CREATION PROCESS OF THE PERSONAS USED IN THE COMMUNICATION CAMPAIGNS OF PORTUGUESE ASSOCIATIONS PARTICIPATING IN THE VIHVER PROJECT

The co-creation process was structured into five stages (Figure 1): (a) preliminary work: joint identification of the main target groups and communication objectives; (b) personas and briefing preparation: collaborative development of patient insights based on persona profiles and preliminary actionable ideas; (c) ideation sessions: each project team (i.e. each association) work independently with the participating pharmaceutical company to brainstorm and shape the final creative brief; (d) challenge: briefing session and project definition, including the setting of goals, key messages, intended outcomes, and communication channels; (e) final results: development of six communication campaign projects, each targeting a specific patient population.

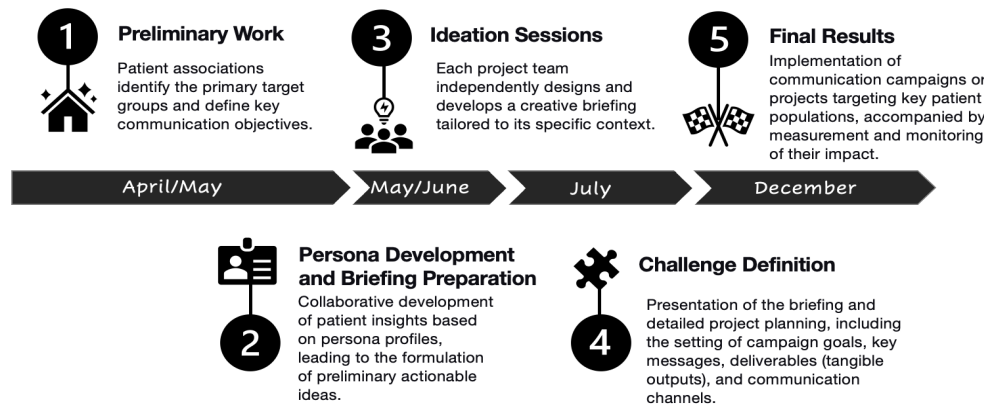


Figure 1. Phases and timeline of the co-creation process

Preliminary work: this initial phase involved each participating association or working group collaboratively defining the key topics and objectives for their campaign. They also identified the primary target populations and selected the most appropriate communication formats to reach them (see Table 2).

ASSOCIATION	TOPIC & OBJECTIVE	TARGET POPULATION	FORMAT
PORTUGUESE ASSOCIATION FOR THE PREVENTION AND CHALLENGE OF AIDS	Improve and increase health literacy on the message “undetectable = untransmittable” among people living with HIV (PLHIV).	PLHIV followed in hospital consultations and at SER+, and health professionals involved in both contexts.	Leaflets, posters, digital media.
PORTUGUESE ACTIVIST GROUP ON TREATMENTS	Increase health literacy and promote adherence to treatment and medical follow-up.	PLHIV experiencing difficulties accepting their diagnosis and adhering to treatment, followed at São Bernardo's Hospital.	Creation of an online chat vs a WhatsApp channel for clarifying general queries and checking dates of tests, consultations, and pharmacy availability of medication (e.g., number of boxes).
PORTUGUESE LEAGUE AGAINST AIDS	Ageing in PLHIV; social stigma and self-stigma associated with the infection; psychiatric comorbidities; a global perspective on health and quality of life; and the need for integrated interventions. Objectives: promote the concept of “holistic health”; reduce stigma; and improve treatment adherence.	General adult population.	Online social networks, YouTube, media, and television in referral hospitals and local health units.
ASSOCIATION FOR COMMUNITY INTERVENTION, SOCIAL DEVELOPMENT, AND HEALTH	Reduce the risk of HIV infection and promote HIV screening.	People engaging in sexual behaviours that increase HIV risk, particularly young men in the African community.	Distribution of condoms with attractive and informative packaging designed by the team; video campaign promoting safer sex featuring a public figure who resonates with the target group.
HUMANITARIAN ASSOCIATION FOR HEALTH AND SOCIAL SUPPORT	Basic information about HIV. Objective: to increase HIV literacy.	PLHIV and their families, with particular attention to individuals from socially and economically disadvantaged backgrounds, including migrant communities.	Postcards with appealing images and messages; each postcard addressing a specific message and theme.
ASSOCIAÇÃO ABRAÇO	Reduce stigma and discrimination related to HIV within families due to a lack of information among informal carers.	Family and social support networks.	Flyer or informational brochure in both paper and digital formats.

Table 2. Preliminary work phase results

Personas and briefing preparation: at this stage, a training session was held (on May 2, 2022) to consolidate information on patient segmentation and relevant insights. Based on data collected during the preliminary work phase and her experience in advisory committees of the participating pharmaceutical company — with leading HIV opinion leaders on PLHIV and specific populations — the trainer assigned a persona to each association. A detailed booklet was provided, outlining the key elements to be considered. Participating associations were asked to (a) describe a typical day in the life of the assigned persona; (b) identify emotionally significant moments — both positive (“moments of magic”) and negative (“moments of misery”); (c) list the persona’s favourite and taboo words; (d) indicate preferred and prohibited brands, shops, and product types; (e) specify preferred and rejected platforms, and describe the persona’s media consumption habits; (f) suggest a public or fictional figure who could hypothetically represent the persona; and (g) detail the habits, needs, frustrations, and behavioural patterns of their current users, including frequency of visits and typical triggers (i.e. where the engagement journey begins). To construct these personas, associations drew on a range of tools and sources, including bibliographic research, questionnaires for health professionals, *in-situ* professional experience, reflections based on that experience, and focus groups involving users and healthcare providers.

With regard to campaign design, participants were informed that the first step is to define the objective. Examples provided included raising awareness, educating on a topic, changing behaviours, or informing the public about available services. Associations were then asked to identify the specific objective(s) of the campaign they intended to conduct. They were also invited to articulate the “big idea” — the central message designed to persuade the target audience to feel, think, or act in a desired way. In the final part of this phase, several guiding questions were posed: who is the target audience (who is this initiative aimed at)? What is the main objective? How will you reach your target audience? What is the big idea? What are the key messages to be communicated? Which channels should be used?

Ideation sessions: the third phase, conducted in June 2022, focused on ideation and involved structured reflection guided by targeted questions, which supported the collection of responses and formative notes. At the outset, each group revisited the persona they had previously developed, along with the associated topic, objective, target population, and preferred communication format. Concepts of design thinking were also introduced at this stage (Figure 2).

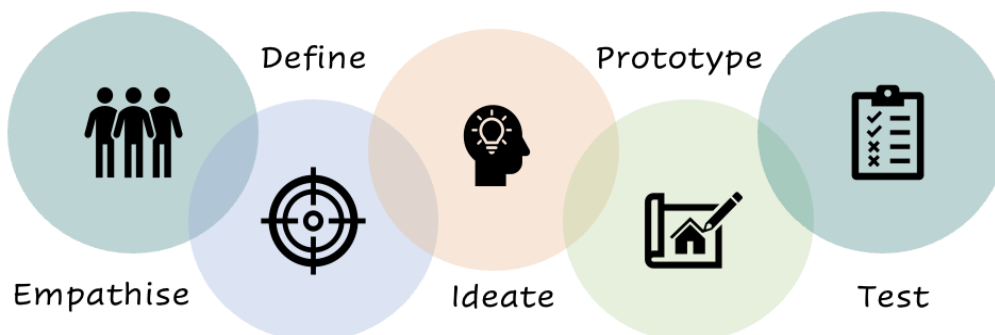


Figure 2. Design thinking

The association is invited to describe the profile of the persona — the typical patient they aim to reach with the campaign. They are then asked: how will the campaign materialise? Several formative notes are provided to support a competent response to this question. These include: “you need to know how to communicate health” and “keep the message simple and relevant”. Within the principle of simplicity, guidelines are offered, such as using “direct, easy-to-understand language, avoiding complex terms or excessive factual detail” and “short, respectful sentences that do not patronise the audience”. To ensure the message is relevant, the following recommendations are emphasised: “connect the world of health to everyday life”, “know your audience to uncover relevant, actionable insights”, “appeal to the emotional side”, “communicating with impact involves answering five key questions: 1. Why? Focus on the benefits and the problem being solved. 2. Who? Who will benefit, and who needs to hear this message? 3. What? What will be done — what is the idea? 4. How? In what format, through copy and action, does the idea materialise? 5. Where? Through which channels can the audience be reached?”.

The training session continued by focusing on the inspirational aspect of campaigning and the importance of generating engagement. A variety of campaign examples from different countries were presented to illustrate what it means to communicate with impact. These included: a poster on HIV created by the Brazilian non-governmental organisation Life Incentive Group; a freelance project by a Filipino illustrator who designed posters to promote sex education in schools; a series of brochures on sex education produced by the United Nations Population Fund and distributed in Kazakhstan; a digital campaign by the Yugoslav Youth Association Against AIDS (JAZAS) to promote condom use; an HIV prevention video by the Hellenic Society for the Study and Control of AIDS; a video series by the French organisation Santé Publique France to raise awareness about medical advances in HIV treatment, to combat discrimination and to show how people can live well with HIV, encouraging them to write a letter to themselves on the day they received their diagnosis; a range of infographics and comic strips; the website of the United States Centers for Disease Control and Prevention, designed to provide topic-specific information for those seeking detailed insights into HIV and what it is like to live with the virus; the UNAIDS website — a United Nations initiative — which shares visual, interactive first-person stories from HIV survivors around the world; and a range of webinars, live conversations on online social networks, and first-person testimonial videos promoted by HIV.gov in the United States.

The training session also covered the following content: (a) key elements of communicating health with impact; (b) components and principles of design thinking; (c) the “what if?” step, which involves brainstorming ideas and concepts; the “napkin pitch” (the big idea — describe the concept; needs/benefits — which stakeholder wants it?; what unmet needs does it address?; how will stakeholders benefit?; how will we benefit?; execution — how will we make it happen?; what assets or capabilities are required to leverage this initiative?; justification — how will this initiative address the identified opportunity? What makes us capable of executing it?); (d) the “what impresses?” step,

which includes assumptions (value test — do patients want it? Do partners want it? Will patients use it?; execution test — can we deliver the content? Is it feasible?; scale test — can it be scaled to other regions?); (e) the design briefing for the agency (including project description, scope, campaign objective, target users, key messages, mandatory elements, channels, restrictions, expected results, and success metrics), and design criteria (design objective, user perception, physical attributes, functional attributes, and constraints); and, finally, (f) the prototype mock-up. The briefing template was provided to all associations.

Challenge: in this challenge and briefing phase, the results of the ideation exercises and decisions related to the co-creation of personas were compiled (Table 3, Table 4, Table 5, Table 6, Table 7, and Table 8). The briefings were presented to the communication agency, marking the start of the iterative process between the agency and the associations. The creative team was tasked with constructing the visual representation of the persona, accompanied by a graphic rationale.

PERSONA PROFILE	Adult individuals of both sexes have self-esteem but feelings of discrimination.
CAMPAIGN OBJECTIVE	Improve communication and mutual understanding for people living with HIV and health professionals regarding the health benefits of HIV control; increase health literacy by disseminating and deconstructing the message “undetectable equals untransmittable (U=U)”; reduce stigma and discrimination.
BIG IDEA	“I am not the virus”.
PERSONA NAME AND PROFILE	Approximate age: 33, reflects the average age among the technicians involved and is population-representative; gender: gender-neutral, inclusive of all identities; geographical location: Cascais; profession: any and/or none; relationships: any and/or none; personality/psychological profile: high self-esteem and well-adjusted: “I like myself”; fears/concerns: discrimination; barriers to changing prejudices: stigma linked to misinformation; strengths (even if not immediately visible): I like who I am, and I am not ashamed of being HIV-positive. I want people to see me for who I am, as more than the virus. I want to have a child. I want to grow old with the person I love, who loves me back. Living with HIV does not prevent me from achieving any of this.
PERSONA DEVELOPMENT PROCESS	Review of scientific literature aligned with SER+’s vision. Evaluate the results of the questionnaire distributed to the healthcare professionals involved, covering (a) their understanding of the U=U message; (b) whether they communicate it; (c) to whom and in what contexts; (d) questions the message may prompt; (e) concerns about the content or its reception by certain populations; (f) use of appropriate support materials to assist in conveying the message. Develop targeted content and materials to be displayed at strategic points — such as the consultation office reception and waiting room — as conversation starters, allowing individuals to ask questions, clarify doubts, and verify their understanding of the U=U message. Provide initial training for the professionals involved, focused on the U=U message and the communication strategy, including guidance on using the materials developed.
JUSTIFICATION	The persona emerged from collective reflection and personal insights drawn from our professional experience with people PLHIV at SER+ and the Immunodeficiency Clinic at Cascais Hospital. It reflects how these individuals perceive, understand, and are informed about the message “U=U”. Given that U=U is a message of empowerment and resilience, it is important to ask: <ul style="list-style-type: none"> • Are all PLHIV attending these two institutions aware of the U=U message? • Do all users fully understand its meaning? • Are all healthcare professionals at these institutions consistently communicating this message? • Will the message be clearly understood by everyone it reaches?

Table 3. Portuguese Association for the Prevention and Challenge of AIDS

CAMPAIGN OBJECTIVE	Increase health literacy and promote adherence to both consultations and treatment; highlight the benefits of consistent adherence and the risks of non-adherence; disseminate and reinforce the message “undetectable = untransmittable” (U=U); encourage individuals to reflect on and self-assess their adherence; improve user engagement and commitment to regular consultations and to antiretroviral therapy; ensure user satisfaction with consultations and enhance treatment retention; evaluate user satisfaction with the consultation process; monitor and assess user adherence following the consultation intervention; implement targeted intervention for people living with HIV (PLHIV) followed at São Bernardo’s Hospital and supported by the Portuguese Activist Group on Treatments who face challenges with therapy adherence.
BIG IDEA	Develop support materials for use in therapy adherence consultations aimed at encouraging adherence and addressing barriers to its effectiveness; establish a dedicated consultation focused on promoting therapy adherence to identify and overcome obstacles, explain the importance of adherence, and clarify the risks associated with non-adherence.
PERSONA PROFILE DESCRIPTION	Male individuals; heterosexual men aged 50 and over face challenges in accepting the diagnosis and adhering to therapy; they often have low educational levels and limited literacy, may have difficulties travelling to healthcare services, and frequently face economic hardship; couples: typically experienced patients with a history of poor adherence; may include individuals who use drugs and those who are polymedicated.
JUSTIFICATION	Provide accurate, reliable information in clear, accessible language; leverage proximity and ongoing contact with the target population.
BENEFITS	Establishment of a multidisciplinary consultation team dedicated to promoting adherence; direct benefit for PLHIV and regular users of consultations.
TARGET POPULATION	PLHIV followed at São Bernardo’s Hospital; PLHIV who are facing challenges with therapy adherence for various reasons — with the aim of identifying and addressing these issues to improve treatment outcomes.
CAMPAIGN REQUIREMENTS	Use accessible, direct, and non-stigmatising language; appeal to emotional awareness; place the individual within their socio-economic context; address and reduce fear; encourage greater engagement from the individual without fear.
OTHER INVESTMENTS	Creation of an online chat <i>versus</i> a WhatsApp channel for clarifying general queries and checking dates of tests, consultations, and pharmacy availability of medication (e.g., number of boxes); establishment of a dedicated consultation focused on promoting therapy adherence to identify and overcome obstacles, explain the importance of adherence, and clarify the risks associated with non-adherence.

Table 4. Portuguese Activist Group on Treatments

CAMPAIGN OBJECTIVE	Raise awareness among people living with HIV about mental health, quality of life, and well-being issues in the context of HIV, focusing both on prevention and integrated intervention.
BIG IDEA	Information: a vaccine against prejudice and stigma? Engagement and sharing: a vaccine against loneliness and isolation? Humour and affection: a vaccine against depression?
PERSONA NAME AND PROFILE	Joaquim, 57, designer, divorced, two children (aged 27 and 23), unemployed for two years, lives with his parents; he was diagnosed with HIV at the age of 35, which led to the crisis that caused the couple to separate when he was 40. The subsequent period was marked by anguish due to the difficulties his ex-wife created in maintaining a close relationship with his children; he sought to cope with his loneliness and discomfort through unprotected sex with multiple partners, avoiding emotional stability. Three years later, he had an acute episode of suspected pneumonia, leading to hospitalisation and the recommendation to begin antiretroviral therapy. Until then, he had kept his health condition entirely secret, concealing his concerns and trying to appear well. Professionally, he began to withdraw and miss deadlines, putting his job at risk. Despite friends warning him about the destructive path he was on, he never sought psychiatric or psychological support. Two years ago, he lost his job and moved back in with his elderly parents due to financial hardship. More recently, he became aware of feeling sad and hopeless, with a growing fear of ageing and the impact of the disease. He stopped attending appointments and abandoned therapy, convincing himself that nothing was worth the effort anymore. He was eventually readmitted to the hospital and referred for psychiatric care.
PERSONA DEVELOPMENT PROCESS	Individual reflections: focus groups with four users (two men and two women) and two health professionals (psychiatrist and clinical psychologist) to understand concerns and needs; formation of a specific working group (association + health professionals).

Table 5. Portuguese League Against AIDS

PERSONA PROFILE	Male individuals, aged around 40, who are sexually active and engaging in risky sexual behaviour, with a specific focus on the African community.
CAMPAIGN OBJECTIVE	Increase health literacy about HIV; reduce transmission risks; promote changes in sexual behaviour, encouraging condom use and adherence to medication; foster HIV screening.
BIG IDEA	Consistent and continuous condom use; prevention of HIV and other sexually transmitted infections; promotion of HIV screening; demystification of beliefs, taboos and myths in African communities living in Portugal regarding condom use, aiming to promote safer sex.
PERSONA NAME AND PROFILE	Approximate age: 43 years old; gender: male; habits/behaviours: risky sexual behaviour, extramarital relationships; geographical location: living in Lisbon, originally from Guinea-Bissau; profession: construction worker; sexual orientation: heterosexual; personality/psychological profile: disconnected from routine healthcare; low perception of infection/disease risk; low health literacy; fears/concerns: being perceived as “weak” or “less masculine” for reducing the number of sexual partners or using condoms; barriers to changing prejudices: low health literacy, reduced risk perception, cultural resistance to condom use; strengths: potential to change behaviour if appropriately informed; capacity to disseminate health information to peers at similar risk.
PERSONA DEVELOPMENT PROCESS	Group meetings aimed at selecting the persona profile most representative of patients who would benefit from targeted intervention, based on the daily community work of the Association for Community Intervention, Social Development, and Health.
JUSTIFICATION	The Association for Community Intervention, Social Development, and Health and Professor Doutor Fernando Fonseca’s Hospital have an established partnership serving the municipalities of Amadora and Sintra. Within the HIV context, the sub-Saharan African population is significantly represented and presents specific social, cultural and linguistic challenges. Daily work involves continuous efforts to bring this community closer to healthcare, ensuring retention and adherence to treatment. This includes combating stigma and demystifying preconceived ideas about HIV while also supporting legalisation processes and socio-occupational integration. Given that most new HIV cases are among heterosexual men around the age of 40, this subgroup has been prioritised for prevention and testing promotion.
MOMENTS OF MAGIC	Being with a group of friends; pride in their children’s achievements; supporting their family through their work.
MOMENTS OF MISERY	Stigma associated with HIV; having to justify work absences; health expenses; economic concerns about their children’s future.
FAVOURITE WORDS	“Family”, “children”, “sex/pleasure”.
TABOO WORDS	“Misery/poverty”, “lack of money”, “giving up”, “illness”, “dependence/physical disability”.
PREFERRED PLACES	Cultural association, shopping centre, neighbourhood café, sports group.
PROHIBITED SHOPS	Luxury shops, travel agencies, restaurants, hospitals.
DOCTOR/ ASSOCIATION RELATIONSHIP	Empathetic doctor-patient relationship; decentralised consultations; after-hours follow-up.
FRUSTRATIONS	Stigma and discrimination; job insecurity; inability to share health status with family and friends.
NEEDS	Accept and integrate information into everyday life; take responsibility for safe sexual behaviour; receive information tailored to their literacy level; overcome cultural barriers to HIV prevention and diagnosis.

Table 6. Association for Community Intervention, Social Development, and Health

PERSONA PROFILE	Female individuals, primarily working women.
CAMPAIGN OBJECTIVE	Increase health literacy about HIV; normalise living with HIV without diminishing the significance of the infection; promote health literacy, particularly in relation to HIV, and reduce self-stigma; contribute to the empowerment of these women; the postcards are intended to serve as tools for professionals from the Infectious Diseases Service and the Humanitarian Association for Health and Social Support to engage in dialogue with users, provide information, clarify doubts, and deconstruct myths and prejudices related to HIV. Users may take the postcard home if they wish. The reverse side can include useful contact information, such as the telephone number or email address of the service, following an information session. Importantly, the postcard itself makes no direct reference to HIV.
BIG IDEA	The quality of life which is made possible through adherence to treatment; normalising HIV status and promoting a positive outlook on living with HIV; “undetectable = untransmittable” (U=U); longevity and sustained well-being; emphasis on the fact that HIV is not transmitted through social contact and reinforcing the importance of commitment to treatment.
PERSONA NAME AND PROFILE	Of African origin (predominantly Guinea-Bissau, though also from other Portuguese-speaking African countries); low literacy levels (many are young and some are illiterate, particularly among women from Guinea-Bissau; basic education up to 9th grade is most common); financially disadvantaged; largely dependent on their husband, partner, or family for survival, including housing and food; face language barriers, with limited proficiency in Portuguese (both spoken and comprehension); often employed in precarious and poorly paid jobs, typically with demanding schedules (e.g., multiple cleaning jobs); frequently live in irregular legal situations (e.g., without residence permits); typically reside in rented rooms within shared housing, where privacy is limited; live in fear that others — including husbands, parents, or children — may discover their HIV status due to significant real and perceived stigma; come from predominantly patriarchal societies and, in the case of Guinea-Bissau, often from polygamous family structures. As these women gradually integrate into the country, they begin to acquire new skills and develop greater awareness of their rights as women. Engaging in dialogue with a healthcare professional about their condition represents a crucial step toward improving health literacy and, ultimately, reducing internalised stigma.

Table 7. Associação Humanitária de Saúde e Apoio Social

PERSONA PROFILE	Informal caregiver.
CAMPAIGN OBJECTIVE	To increase health literacy about HIV among informal caregivers in order to reduce stigma and fears associated with both caregiving and receiving care.
BIG IDEA	I am more than HIV.
PERSONA NAME AND PROFILE	Hugo Barata is 68 years old, widowed, retired, and living with his son in Porto; he is entirely analogue; Hugo spends all day at home looking after his son, tidying the house, and ensuring everything is clean and disinfected — drawing a parallel with the children’s story <i>Finding Nemo</i> , in which Marlin is the anxious father of little Nemo; when Hugo needs to leave the house (only to visit the local grocery shop), he asks a neighbour to watch over his son.
QUOTE	“He’s my son. I do everything; I’m very careful because I don’t want to get sick myself”.
MOMENTS OF MAGIC	Being able to go out to the grocery store; reading his daily newspaper.
MOMENTS OF MISERY	Having to carry his son in his arms; changing his son’s nappy; bathing his son; missing his wife.
FAVOURITE WORDS	“I love you, Dad”; “Do you need help?”.
TABOO WORDS	“My son has HIV”.
PREFERRED PLACES	The neighbourhood grocery store.
PROHIBITED SHOPS	All other shops within a five-minute walk from home.
DOCTOR/ ASSOCIATION RELATIONSHIP	“I don’t always go to appointments because the ambulance is very expensive”.

MOTIVATIONS	To have time to take care of himself; to feel rested and reassured that everything is okay.
FRUSTRATIONS	Not knowing who can help; having no one to look after his son if he were to die; anxiety about financial matters; believing HIV is transmissible even when undetectable; excessive disinfection measures to avoid infection; fear of falling ill.
NEEDS	Support from a private social welfare institution to provide home care, enabling Hugo to have free time during the day; reliable information about HIV to simplify daily life (e.g., Hugo washes his son's clothes and dishes separately and overdoes disinfection); clear guidance about HIV in order to improve his son's quality of life (e.g., allowing him to leave his room and spend more time together without fear of transmission); understanding the message "undetectable = untransmittable" (U=U).
NARRATIVE	Hugo has been living with his son, who is HIV-positive, for 12 years. His wife passed away three years ago, and his son now relies on him entirely for day-to-day care. Hugo provides all basic care — including feeding, bathing, and lifting — but lives in constant fear of becoming infected. Although his son's HIV is undetectable, related complications have made him highly dependent. Hugo also struggles with his own health problems, including high blood pressure and high cholesterol, and experiences intense loneliness.

Table 8. *Associação Abraço*

Among the reactions of health professional associations to the process of co-creating personas, several positive aspects stood out. One was the “humanisation of people living with HIV” (SER+). It was emphasised that “the persona created reflects a real identity, with desires, aspirations and autonomy, demystifying stigmas associated with the infection and promoting resilience and self-confidence through the message ‘undetectable equals untransmittable’”. This approach reinforces the idea that “being HIV positive does not define a person, nor does it prevent them from having a full life, with relationships, children and a healthy future”. Additionally, the impact of “amplifying the voices of many individuals who identify with our persona, thereby enabling the message to reach further and resonate more deeply” (AJPAS) was highlighted. Another key point was the “importance of non-discrimination rights for those receiving care” (Abraço/Santo António’s Hospital), which underscores the need to combat prejudice and ensure equal treatment.

On the other hand, the associations and health professionals involved in the persona co-creation process identified several challenges. One of the difficulties mentioned was “combating prejudice and ensuring that the persona authentically and accessibly represented the reality of people living with HIV” (SER+). Striking a balance between technical and emotional content was particularly demanding, with the aim of making the message clear “without reinforcing stereotypes, but rather promoting inclusion and empathy” (SER+). Another challenge concerned “conveying a clear message, bearing in mind that the persona was not a person living with HIV, but a carer of someone who is” (Abraço/Santo António’s Hospital), which required additional sensitivity in constructing the narrative. Moreover, there was the complexity of “attempting to demystify a stereotype without offending certain beliefs, taboos, or myths associated with HIV” (AJPAS), highlighting the care and nuance required to address the topic both responsibly and effectively.

8.2. PERSONA LANGUAGE IN CAMPAIGNS BY PORTUGUESE ASSOCIATIONS IN THE VIHVER PROJECT

The dominant colours used in the campaigns are yellow and magenta — vibrant tones that evoke energy and dynamism, as well as conveying warmth and happiness (agency graphic rationale). Yellow, in particular, is commonly associated with joy, optimism, and vitality, reinforcing a sense of positivity and the supportive environment essential for people living with HIV+. Its presence suggests hope and the possibility of a good quality of life (graphic rationale). This symbolic meaning is especially evident in the description of the SER+ persona. Traditionally linked to sunlight, yellow also connotes illumination, dissemination, and a universal or inclusive scope (Cirlot, 2001). Moreover, yellow is perceived before other colours — especially against black — a combination frequently used in warning signs and culturally associated with inexperience, gullibility (myths), immaturity, or strangeness (Feisner, 2006). This chromatic pairing features in the construction of nearly all personas in the project, with the exception of SER+ and AHSeAS, where yellow is restricted to the background.

Magenta is a vibrant colour associated with empathy, compassion and care (agency graphic rationale). Symbolising solidarity and support, it evokes the figure of the caregiver (graphic rationale). In the chromatic hierarchy, magenta is considered the royal colour (Seiler-Hugova, 2011) — a “queen” among colours — and, in alchemical terms, represents the quintessence of the four elements (earth, water, air and fire), thus standing for a pure and divine substance. As such, it conveys a sense of intensification and transcendence of all colours, symbolising plurality, diversity, inclusion, coexistence, communion and wholeness.

The stylised shapes employed in the campaigns are intended to suggest modernity and progress (graphic rationale). Their interpretative openness conveys values such as flexibility, adaptability and inclusion (graphic rationale). The design also embraces simplicity, aiming to evoke an emotional connection and to communicate, with ease, the essence of human diversity. It celebrates the uniqueness of each individual and highlights the beauty inherent in difference (graphic rationale).

The use of the expression “hello” in each persona’s self-introduction functions as an attention-grabbing device (Elliott, 2007), offering a friendly, more engaging way to connect with consumers (Adamson, as cited in Elliott, 2007). The framing adopted in these self-introductions tends to be negative, foregrounding each persona’s vulnerabilities. This approach — evident in four of the six personas (as opposed to positive or neutral framing) — contributes to fostering identification and projection on the part of the audience.

In sum, the study demonstrates that the co-creation of personas was a structured and representative process, innovative in form and guided by principles of health literacy. A set of six distinct personas was developed, each reflecting a different profile of PLHIV, thereby enabling more targeted and customised communication. The findings highlight the centrality of verbal, visual, and stylistic choices in shaping the character of each persona. Narrative elements, such as the personas’ self-introduction and the humanisation of their everyday experiences, enhance the potential for audience identification. Ultimately,

the study underscores the importance of co-creation in designing communication campaigns that are better attuned to the needs and realities of the communities they serve.

9. DISCUSSION OF FINDINGS

Co-creating personas followed a structured, phased process with clearly defined stages, which is common in other co-creation initiatives (Pearce et al., 2020) and persona creation (e.g., Vosbergen et al., 2015). Regarding co-creation practices, and in line with Frow et al.'s (2016) typology, the co-creation process within the VIHVER project encompassed all types except for “practices that are intentionally co-destructive”. Notably, the following can be highlighted in this project: (a) practices that build social capital for participants, facilitating access to social resources such as connections, shared knowledge, social norms, information, and mutual support through interpersonal relationships; (b) practices that provide a shared language, symbols, signs, and stories within the ecosystem, exemplified by the creation of personas with their unique graphic language; (c) practices that influence actors' mental models, such as brainstorming, ideation exercises, and sharing diverse experiences and information; (d) practices that impact the ecosystem by engaging with the physical structures and institutions relevant to the context, as the VIHVER project directly involves stakeholders related to HIV and AIDS to enhance health literacy on these topics; (e) practices that refine and inspire new value propositions, as this co-creation effort specifically focused on HIV and AIDS can serve as a model for health literacy initiatives targeting other diseases, viruses, or health issues; (f) practices that improve access to resources within an ecosystem, with the VIHVER project aiming to increase access to knowledge and resources, including support from health professionals, screenings, and condoms; (g) practices that foster new relationships, generating interactive and/or experimental opportunities that can be replicated in future co-creation efforts.

As in the study by Dzinamarira et al. (2020), the VIHVER project involved both representatives of the target population (namely, associations) and health professionals in the co-creation process. Similarities can also be observed in the barriers identified, which include fears and misconceptions around traits deemed masculine (LPCS, AJPAS), self-stigma (AHSeAS), and fear of stigma or discrimination (SER+, LPCS, AJPAS, AHSeAS, Associação Abraço). Echoing the approach of Teleman et al. (2022) — though their focus was on personas representing children with disabilities — the VIHVER project conducted co-creation workshops, equipped participants with relevant skills, and adjusted personas throughout the process. It produced both narrative profiles and concise, descriptive phrases to capture each persona's character.

In terms of language and its application in the co-creation process, the project adhered to the principle that personalisation is essential to achieving specific outcomes (e.g., Galliford et al., 2022). Accordingly, each participating association developed its persona tailored to the profile of its typical user. Several methodological guidelines aligned with existing literature were adopted: (a) structuring the process into formative research and

evaluative phases, including observation and immersion in the relevant context; (b) modelling personas on real-life individuals (Massey et al., 2021); (c) grounding the personas in data, including sociodemographic and behavioural dimensions (Giunti et al., 2018), as well as motivations, concerns, and core interests of patient archetypes (Maguire, 2001); (d) describing the type of patient the persona represents by including a personal history and narrative structure that outlines actions and decisions (Bhattacharyya et al., 2019; Neate et al., 2019); and (e) including a visual representation, whether a graphic sketch or a photograph. These methodological choices also serve as potential recommendations from this study, alongside (f) the importance of understanding segmentation and patient insights; (g) the need for knowledge of campaign design (e.g., identifying goals, core concepts, key messages, target audiences, and appropriate communication channels); (h) familiarity with the creative process; and (i) careful attention to the visual and verbal presentation of the personas, including colour, form, language, and the setting used to characterise them. The results address the theoretical gaps identified at the outset of the article, namely the limited research on the use of personas in health communication and the lack of transparency in co-creation processes. This study contributes a structured co-creation model, outlining each stage — from defining the target audience to crafting final messages. Furthermore, it supports the premise that personalisation enhances the effectiveness of health literacy campaigns (e.g., Galliford et al., 2022; Massey et al., 2021) while also demonstrating the practical application of co-creation as a tool for community empowerment (e.g., Araújo et al., 2019; Silva et al., 2023).

In doing so, the study responds to frequent criticism in the literature regarding the insufficient clarity and depth in reporting co-creation practices in health contexts. Even the work of Vosbergen et al. (2015) — which explored the use of personas to adapt educational messages for patients with coronary heart disease and attempted to describe the co-creation process — appears less ambitious, having focused solely on two sub-phases: segmentation and persona identification.

10. CONCLUSION

This research documents a persona co-creation experience that is: (a) plural and highly representative, involving six associations linked to HIV and AIDS, thereby enabling the sharing and cross-fertilisation of experiences; (b) useful, as it equipped participating organisations with methodological knowledge — including deep diving into personas and briefing communication agencies; (c) instructive, by offering a clear *modus operandi* and a set of practical recommendations; (d) grounded in health literacy and behavioural sciences, with content tailored to specific segments, communicated in accessible and comprehensible language; (e) replicable, due to the detailed account of each phase and its applicability to other health literacy and awareness initiatives involving diseases, viruses or public health challenges; (f) transferable across contexts, as it may be implemented in both national and international settings where similar profiles exist; (g) a legacy, insofar as the mentor of the intervention (the participating pharmaceutical

company) provides each partner with tools and skills to address future topics and challenges; (h) innovative, marking the first time in Portugal that stakeholders involved in supporting PLHIV at various levels have collaboratively developed content to address their needs; and (i) committed to promoting the 17th United Nations sustainable development goal, which fosters partnerships to achieve more consistent, inclusive, and widely recognised outcomes, contributing to a more constructive and collaborative approach to health communication.

The present study offers both theoretical and practical contributions. On a theoretical level, it addresses key gaps in the literature by providing a detailed and transparent account of the persona co-creation process in health literacy campaigns focused on HIV and AIDS. By rigorously documenting each stage, the study not only systematises a replicable methodological protocol but also reinforces the effectiveness of personas as a strategic communication tool. It further contributes to the development of participatory research by demonstrating how co-creation can enhance awareness-raising strategies. On a practical level, the study validates the applicability of the persona co-creation model as a transferable tool for other public health campaigns. It also supports the advancement of health literacy by evidencing the impact of linguistic and visual choices and offering concrete guidelines for future communication initiatives. Additionally, the active involvement of community associations in the process fostered capacity building, providing them with valuable experience and training.

Despite the relevance of this study, several limitations should be acknowledged. Firstly, the qualitative nature of the research restricts the transferability of the findings to broader contexts. Although the co-creation process is thoroughly documented, applying the model in other countries or health domains may require context-specific adaptations. Secondly, the study relies heavily on the collaboration of associations and health professionals. While this enriched the research, it may also introduce a degree of selection bias. The active involvement of associations was crucial to persona development; however, the diversity of profiles among PLHIV may not have been fully captured, given the varied characteristics of the associations' users. Finally, the study did not include a quantitative assessment of the campaigns' impact. Future research could incorporate metrics to evaluate the effectiveness of the co-created personas and messages, providing a more robust analysis of their influence on the target audience.

Translation: Anabela Delgado

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BIOGRAPHICAL NOTES

Cristina Vaz de Almeida holds a PhD in Communication Sciences, with a specialisation in Health Literacy, from the School of Social and Political Sciences, University of Lisbon. She is president of the Portuguese Society of Health Literacy, director of the postgraduate programme in Health Literacy at the Institute of Applied Psychology, and a founding member of the Portuguese Lab for Healthy Workplaces. She serves as editor-in-chief of the *Jornal Investigação Médica* and is a peer reviewer for the *Portuguese Journal of Public Health*. Vaz de Almeida is a researcher at the Centre for Public Administration and Public Policies and a member of several national and international bodies, including the Advisory Board of the *BUMPER* project, the National Cancer Hub – Portugal, the Portuguese Council for Health and Environment, the Scientific Council of the *Journal of Psychology and Neuroscience*, and the Academic Network of Health Sciences. She is also the coordinator and lead author of the *Manual de Literacia em Saúde – Princípios e Práticas* (Health Literacy Handbook – Principles and Practices), published by Pactor.

ORCID: <https://orcid.org/0000-0001-5191-1718>

Email: vazdealmeidacristina@gmail.com

Address: Instituto Superior de Ciências Sociais e Políticas, Polo Universitário do Alto da Ajuda, R. Almerindo Lessa, 1300-663 Lisboa, Portugal

Ana Correia is a nurse and technical coordinator at the Portuguese Activist Group on Treatments. She holds a degree in Nursing from the Polytechnic University of Leiria – School of Health Sciences (2016). Between 2016 and 2020, she was actively involved in the project *Sidade Alerta*.

ORCID: <https://orcid.org/0009-0005-2021-3024>

Email: ana.correia@gatportugal.org

Address: Avenida Paris, 4 – 1.º Direito 1000-228 Lisboa, Portugal

Andreia Pinto Ferreira is a strategic leader with over 22 years of experience in coordinating Portuguese Association for the Prevention and Challenge of AIDS, a Portuguese non-governmental organisation dedicated to HIV/AIDS and viral hepatitis. She holds a degree in Social Work and postgraduate qualifications in Families and Social Systems, as well as in AIDS Studies. She has co-authored scientific studies on quality of life and HIV-related stigma, and her expertise lies in cross-sector project management, organisational modernisation, and social impact, aligned with the sustainable development goals of the 2030 Agenda. She has coordinated initiatives such as the *Fast-Track Cities* programme (UNAIDS) and infection screening efforts within prison and homeless populations. Her work centres on building strategic partnerships, promoting national awareness campaigns, improving the living conditions of vulnerable populations, and combating

discrimination. She previously served as general coordinator of Portuguese Association for the Prevention and Challenge of AIDS, where she contributed to significant progress in the fields of health and social inclusion.

ORCID: <https://orcid.org/0009-0009-0582-6438>

Email: andrea.pinto.ferreira@gmail.com

Address: Rua André Homem, Edifício SER+, n.º 60 2750-783 Cascais, Portugal

Catarina Esteves Santos holds a degree in Nursing (2003) and has specialised in Mental Health and Psychiatry since 2010. She has worked in the field of HIV infection since 2004, with experience in patient-reported outcomes, ageing and mental health, linkage to care, and clinical research. She is the founder of the HIV Nursing Working Group in Portugal (2018) and an active member of the European HIV Nursing Network since 2007, contributing extensively to research and professional training in the field. From 2018 to 2022, she served on the Executive Board of the Portuguese Association for the Study of AIDS. As an HIV consultant, she is regularly invited to speak at national and international conferences and authored several scientific publications. She is widely recognised for her leadership and expertise in nursing care for people living with HIV.

ORCID: <https://orcid.org/0000-0002-4478-1318>

Email: catarina.esteves.santos@hospitalcascais.pt

Address: Av. Brigadeiro Victor Novais Gonçalves, 2755-009 Alcabideche, Cascais, Portugal

Cristina Mora is the technical director and vice-president of the Board of the Humanitarian Association of Health and Social Support.

ORCID: <https://orcid.org/0009-0004-6916-0288>

Email: cristinamora@ahseas.pt

Address: AHSeAS, Praceta José Gomes Ferreira, n.º 2 A 2725-564 Mem Martins, Portugal

Cristina Sousa holds a degree in Social Work. She began her career as a social worker at Joaquim Urbano Hospital in 2003 and joined Abraço in 2006. Since 2020, she has served as president of Abraço.

ORCID: <https://orcid.org/0009-0007-4510-8356>

Email: cristina.sousa@abraco.pt

Address: Associação Abraço - Associação de Apoio a Pessoas com VIH/SIDA — Largo José Luís Champalimaud 4A, 1600-100 Lisboa, Portugal

Diva Trigo has been a medical doctor since 2010, specialising in Infectious Diseases since 2017. She currently practises at Professor Doutor Fernando Fonseca Hospital, where she works across a range of infectious diseases, with a particular interest in HIV/AIDS, tuberculosis, and viral hepatitis. She is also a guest assistant lecturer at the Faculty of Medicine, University of Lisbon, within the University Clinic of Infectious Diseases.

ORCID: <https://orcid.org/0000-0001-9633-6841>

Email: divatrigo@gmail.com

Address: Hospital Professor Doutor Fernando Fonseca, IC19, 276, 2720-276 Amadora, Portugal

Maria Isabel Casella is a hospital assistant in infectious diseases registered with the southern regional section of the Portuguese Medical Association (No. 53762). She holds a master's degree in Medicine from Charles University in Prague, Faculty of Medicine in Pilsen (2005–2011). She completed her internship at Professor Doutor Fernando Fonseca's Hospital in 2012, followed by specialised training in Forensic Medicine (2013–2015) and Infectious Diseases at São Bernardo's Hospital (2015–2022). Since October 2022, she has been working as a hospital assistant in infectious diseases at São Bernardo's Hospital, where she is responsible for the pre-exposure prophylaxis consultation, as well as for decentralised consultations at Pinheiro da Cruz and Setúbal prisons and the Litoral Alentejano Local Health Unit. Since January 2021, she has served as coordinator of Local Unit for the Prevention and Control of Infections and Antimicrobial Resistance at Setúbal Hospital Centre, and she has been a member of its executive board since 2022, with responsibility for the Antimicrobial Prescription Support Programme. She is also actively involved with the Portuguese Activist Group on Treatments – Setúbal, where she has led the sexually transmitted infections consultation since October 2021.

ORCID: <https://orcid.org/0000-0001-9744-8044>

Email: isabelgat22@gmail.com

Address: Hospital de São Bernardo — R. Camilo Castelo Branco 175, 2910-549 Setúbal, Portugal

Josefina Mendez Vazquez is an infectious disease specialist at the Porto University Hospital Centre.

ORCID: <https://orcid.org/0000-0001-5786-3809>

Email: josefinamendezvazquez@gmail.com

Address: Associação Abraço - Associação de Apoio a Pessoas com VIH/SIDA, Largo José Luís Champalimaud 4A, 1600-100 Lisboa, Portugal

Maria Eugénia Saraiva is a clinical and health psychologist with a degree from the Lusófona University of Humanities and Technologies. She has advanced specialisation in Community Intervention and Sexuality, as well as a postgraduate qualification in Sexually Transmitted Infections, with a focus on HIV/AIDS. A volunteer with the Portuguese League Against AIDS since its foundation, she has been serving as president of the board since 2006. She works as a health project manager, coordinator, and psychologist at Espaço Liga-te and the mobile unit Saúde + Perto. Her work involves the development of projects on sexual health, the prevention of HIV/AIDS, hepatitis, and sexually transmitted infections among vulnerable populations, including men who have sex with men, the homeless, immigrants, and injecting drug users. Co-author of the

Manual de Psicologia da Saúde (Handbook of Health Psychology; 2021), she is an active member of various scientific and social organisations, such as the Portuguese Society of Clinical Sexology and the Health in Dialogue Platform. She is also a promoter of educational campaigns in Portugal and the community of Portuguese-speaking countries, notably through initiatives like Somos pela Saúde. Additionally, she works as a certified trainer for the Institute of Employment and Vocational Training and other organisations, collaborating with Private Social Solidarity Institutions and government bodies.

ORCID: <https://orcid.org/0009-0003-9223-3484>

Email: ma.saraiva@ligacontrasida.org

Address: Liga Portuguesa Contra a SIDA, Praça Carlos Fabião, Loja 3A, 1600-311 Lisboa, Portugal

Patrícia Pacheco holds a degree in Medicine from the Faculty of Medicine of the University of Coimbra. She is a senior assistant in Infectious Diseases and has served as director of the Infectious Diseases Service at Professor Fernando Fonseca's Hospital since 2012. She is also a guest assistant lecturer at the Faculty of Medicine, University of Lisbon and a clinical researcher in the field of HIV infection. She lectures on various training programmes in infectious diseases and is the author of several scientific articles published in national and international journals. She is a member of the governing bodies of the Portuguese Association for the Clinical Study of AIDS — board member (2023–2024) — and of the Portuguese Coinfection Study Group — chair of the General Assembly (2021–2024). She was also a board member of the Portuguese Society of Infectious Diseases and Clinical Microbiology (2017–2020) and, since 2023, has been a member of the National Executive Council of the Portuguese Medical Association.

ORCID: <https://orcid.org/0000-0002-0808-1867>

Email: patricia.p.pacheco@ulsasi.min-saude.pt

Address: ULS Amadora -Sintra, Hospital Professor Fernando Fonseca. IC-19, 276, 2720-276 Amadora, Portugal

Ricardo Fernandes is an activist with two decades of experience in the field of HIV. He holds a degree in Modern Languages and Literature from the Faculty of Letters, University of Lisbon. Since 2000, he has worked with various Portuguese non-governmental organisations, primarily in project coordination and management. He is currently the executive director of the Portuguese Activist Group on Treatments (<https://gatportugal.org>) and has served as president of the European AIDS Treatment Group (<https://eatg.org>). He has co-organised several national conferences and co-authored studies and articles, particularly on stigma, diagnosis and delayed diagnosis.

ORCID: <https://orcid.org/0009-0000-2666-1649>

Email: ricardo.fernandes@gatportugal.org

Address: Avenida Paris, 4 – 1.º Direito, 1000-228 Lisboa, Portugal

Rita Pires is a social work professional with extensive experience in the coordination and management of community-based and social projects. Since 2021, she has served as

technical director of the Association for Community Intervention, Social Development, and Health (AJPAS), leading initiatives in the areas of HIV, hepatitis, tuberculosis, and community screening. From 2015 to 2021, she worked as a social worker at the Portuguese Activist Group on Treatments, focusing on psychosocial support and stigma reduction. She was also the technical director at AlertaMente (2018–2020) and executive director of a residential care facility for older adults (2013–2018). She began her career at the Grupo de Intervenção e Reabilitação Ativa (2011–2017). She holds a degree in Social Work from the Faculty of Human Sciences of the Portuguese Catholic University (2007).

ORCID: <https://orcid.org/0009-0002-8177-4237>

Email: ana.pires@ajpas.pt

Address: Associação de Intervenção Comunitária, Desenvolvimento Social e de Saúde (AJPAS), Praceta Bento de Moura Portugal, s/n.º Bairro Girassol, 2700-109 Venda Nova – Amadora, Portugal

Sílvia Ouakinin is a psychiatrist with a robust academic and clinical background. Since 2021, she has been a guest lecturer at the Faculty of Psychology, University of Lisbon, where she teaches Psychopathology and Emotion. Previously, she served as an assistant professor at the Faculty of Medicine of the University of Lisbon for over two decades (2000–2021). She holds a PhD in Psychiatry and Mental Health from the same institution and has dedicated her career to both higher education and psychiatric practice.

ORCID: <https://orcid.org/0000-0002-2123-9104>

Email: souakinin@gmail.com

Address: Liga Portuguesa Contra a SIDA, Praça Carlos Fabião, Loja 3A, 1600-311 Lisboa, Portugal

Vitalina Silva is president of the Association for Community Intervention, Social Development, and Health. Since 2022, she has also served on the municipal committees of the Amadora City Council, namely as secretary of the Education, Culture, Sport and Youth Committee and as a member of the Social Cohesion, Health, Safety and Civil Protection Committee.

ORCID: <https://orcid.org/0009-0007-0952-7940>

Email: vitalina.silva@ajpas.pt

Address: Associação de Intervenção Comunitária, Desenvolvimento Social e de Saúde (AJPAS), Praceta Bento de Moura Portugal, s/n.º Bairro Girassol, 2700-109 Venda Nova – Amadora, Portugal

Célia Belim is an assistant professor in Communication Sciences at the Higher Institute of Social and Political Sciences, University of Lisbon, where she has been teaching since 2000. She holds a PhD in Communication Sciences, a master's in Political Science, and a postgraduate degree in Islamic Studies. She is currently the deputy coordinator of the Communication Sciences Coordination Unit and teaches across all three academic cycles. She coordinates the funded research project *Comunicação de Políticas Públicas de Saúde em Portugal — ComHealthPPP*, linked to the Centre for Administration and Public

Policy, where she is also a researcher. She is the director and scientific coordinator of the *Revista Portuguesa de Literacia em Saúde* and vice-president of the Scientific Council of the Portuguese Society for Health Literacy. She is co-author of *Health Communication Models and Practices in Interpersonal and Media Contexts: Emerging Research and Opportunities* (2021, IGI Global) and *Image of U.S. Presidential Administrations: The Cases of George W. Bush and Barack Obama* (2012, Lexington Books, Roman & Littlefield). She has received five academic awards, including seven for research and two honourable mentions.

ORCID: <https://orcid.org/0000-0001-9927-8018>

Email: cbelim@iscsp.ulisboa.pt

Address: Instituto Superior de Ciências Sociais e Políticas, Polo Universitário do Alto da Ajuda, R. Almerindo Lessa, 1300-663 Lisboa

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