

Health system readiness assessment and quality of services for dementia in Peru: Study Protocol

Maria Lazo-Porras, Francisco Jose Tateishi-Serruto, Christopher Butler, María Sofía Cuba-Fuentes, Daniela Rossini-Vilchez, Silvana Perez-Leon, Miriam G. Lucar, J. Jaime Miranda, Antonio Bernabe-Ortiz, Francisco Diez-Canseco, Graham Moore, Filipa Landeiro, Maria Kathia Cardenas, Carlos Vera-Tudela, Lee White, Rafael A. Calvo, William Whiteley, Jemma Hawkins, IMPACT Salud study group

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Table of Contents

Original Manuscript	5
Supplementary Files	27
Figures	28
Figure 1	29

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Maria Lazo-Porras^{1*} MD, MSc, PhD; Francisco Jose Tateishi-Serruto^{1*} BA, MPH; Christopher Butler² MD, PhD; María Sofía Cuba-Fuentes¹ MD, DM; Daniela Rossini-Vilchez¹ BA; Silvana Perez-Leon¹ BA, MSc; Miriam G. Lucar¹ MSc; J. Jaime Miranda¹ MD, PhD; Antonio Bernabe-Ortiz¹ MD, PhD; Francisco Diez-Canseco¹ BA, MPH; Graham Moore³ MSc, PhD; Filipa Landeiro⁴ DPhil; Maria Kathia Cardenas¹ BA, MSc; Carlos Vera-Tudela¹; Lee White²; Rafael A. Calvo⁵ PhD; William Whiteley⁶ BM, MSc, PhD; Jemma Hawkins³ PhD; IMPACT Salud study group^{2*}

Corresponding Author:

Maria Lazo-Porras MD, MSc, PhD CRONICAS Centre of Excellence in Chronic Diseases Universidad Peruana Cayetano Heredia Av. Armendariz 445 Lima PE

Abstract

Background: Dementia is a global health priority with significant challenges due to its complex nature and increasing prevalence. Health systems worldwide struggle to address chronic conditions like dementia, often providing fragmented care. However, information about how health systems respond to the needs of people with dementia (PWD) and their carers, and the quality of care provided, is scarce in low- and middle- income countries

Objective: This study aims to understand the response of the Peruvian health system to PWD and their carers as well as to explore the experiences of PWD of receiving their diagnosis, management and quality of care for this condition. Additionally, the study will explore the willingness of the health system and stakeholders to adopt new tools for the diagnosis, management and quality of care of dementia.

Methods: This study is part of a research programme called "IMPACT Salud: Innovations using Mhealth for PWD and Comorbidities", aimed at strengthening health systems to provide care for PWD and their carers. The study has a descriptive, cross-sectional design that uses mixed methods methodology and consists of two sub-studies, a health system assessment and an exploration of the patient journey. The first sub-study employs a health system assessment methodology suitable for low- and middle-income countries, conducting 160 structured interviews with 12 different stakeholder types across three levels of the health system (micro, meso, and macro) in four Peruvian regions, each with distinct geographical and urbanization profile. The second sub-study, utilizes a patient journey methodology, which involves conducting 40 in-depth interviews with PWD, carers, and healthcare workers from the same four regions. The insights into the PWD patient and caregiver experience within the health system from the interviews will be used to produce a patient journey map. The analysis will be guided by the High-Quality Health System Framework and the findings from the health system assessment and patient journey will be structured using the domains included in the framework through the lens of quality of services.

Results: Data collection began in March 2024, aiming to finish by late July 2024. As of end of April 2024, 59 interviews from the health system assessment have been conducted in three regions.

Conclusions: This study will provide a national, multi-level insight into the current operation of the Peruvian health system

¹CRONICAS Centre of Excellence in Chronic Diseases Universidad Peruana Cayetano Heredia Lima PE

²Department of Brain Sciences Imperial College London London GB

³Centre for Development, Evaluation Complexity and Implementation in Public Health Improvement (DECIPHer), School of Social Sciences Cardiff University Cardiff GB

⁴Health Economics Research Centre Oxford University Oxford GB

⁵Dyson School of Design Engineering Imperial College London London GB

⁶Centre for Clinical Brain Sciences University of Edinburgh Edinburgh GB

^{*}these authors contributed equally

including an analysis of the quality of services provide, with regards dementia diagnosis, management and care; from the perspectives of system stakeholders, patients and their carers.

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Original Manuscript

Health system readiness assessment and quality of services for dementia in Peru: Study Protocol

Tateishi-Serruto F.J.^{1*}, Lazo-Porras M.^{1*}, Butler C.^{2,3}, Cuba-Fuentes M.S.⁴, Rossini-Vilchez D.¹, Perez-Leon S.¹, Lucar Miriam G.¹, Miranda J.J.^{1,5}, Bernabe-Ortiz A.¹, Diez-Canseco F.¹, Moore G.⁶, Landeiro F.⁷, Cárdenas M.K.¹, Vera-Tudela, C.¹, White L.², Calvo R.A.⁸, Whiteley W.⁹, Hawkins J⁵, on behalf of the IMPACT Salud Study Group.

Affiliations

- CRONICAS Centre of Excellence in Chronic Diseases, Universidad Peruana Cayetano Heredia, Lima, Peru
- 2. Department of Brain Sciences, Imperial College London, UK
- 3. The George Institute for Global Health, Imperial College London, UK
- 4. Center for Research in Primary Health Care, Universidad Peruana Cayetano Heredia, Lima, Peru.
- 5. Sydney School of Public Health, Faculty of Medicine and Health, University of Sydney, Australia
- 6. Centre for Development, Evaluation Complexity and Implementation in Public Health Improvement (DECIPHer), School of Social Sciences, Cardiff University, UK.
- 7. Health Economics Research Centre, Oxford University, UK
- 8. Dyson School of Design Engineering, Imperial College London, UK
- 9. Centre for Clinical Brain Sciences, Edinburgh Imaging, and UK Dementia Research Institute, University of Edinburgh, UK

Corresponding Author:

Name: Maria Lazo-Porras Email: maria.lazo@upch.pe

Address: Av. Armendariz 445 - Miraflores- Lima

^{*}First co-authors

ABSTRACT

Background:

Dementia is a global health priority with significant challenges due to its complex nature and increasing prevalence. Health systems worldwide struggle to address chronic conditions like dementia, often providing fragmented care. However, information about how health systems respond to the needs of people with dementia (PWD) and their carers, and the quality of care provided, is scarce in low- and middle- income countries.

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This study aims to understand the response of the Peruvian health system to PWD and their carers as well as to explore the experiences of PWD of receiving their diagnosis, management and quality of care for this condition. Additionally, the study will explore the willingness of the health system and stakeholders to adopt new tools for the diagnosis, management and quality of care of dementia.

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This study is part of a research programme called "IMPACT Salud: Innovations using Mhealth for PWD and Co-morbidities", aimed at strengthening health systems to provide care for PWD and their carers. The study has a descriptive, cross-sectional design that uses mixed methods methodology and consists of two sub-studies, a health system assessment and an exploration of the patient journey. The first sub-study employs a health system assessment methodology suitable for low- and middle-income countries, conducting 160 structured interviews with 12 different stakeholder types across three levels of the health system (micro, meso, and macro) in four Peruvian regions, each with distinct geographical and urbanization profile. The second sub-study, utilizes a patient journey methodology, which involves conducting 40 in-depth interviews with PWD, carers, and healthcare workers from the same four regions. The insights into the PWD patient and caregiver experience within the health system from the interviews will be used to produce a patient journey map. The analysis will be guided by the High-Quality Health System Framework and the findings from the health system assessment and patient journey will be structured using the domains included in the framework through the lens of quality of services.

Results:

Data collection began in March 2024, aiming to finish by late July 2024. As of end of April 2024, 59 interviews from the health system assessment have been conducted in three regions.

Conclusions: This study will provide a national, multi-level insight into the current operation of the Peruvian health system including an analysis of the quality of services provide, with regards dementia diagnosis, management and care; from the perspectives of system stakeholders, patients and their carers.

Keywords:

Dementia; health system readiness; caregiver; comorbidities; Peru

Introduction

Health systems worldwide face the challenge of addressing chronic conditions, which in low- and middle-income countries (LMICs) is exacerbated due to resource scarcity. LMICs often respond to diseases in isolation through vertical programmes [1]. A global and integrated response to chronic conditions is needed to provide high-quality care for individuals with complex conditions [2]. Dementia is one such chronic condition, characterized as a complex disorder involving psychosocial dysfunction and vulnerability due to brain disease [3]. Dementia is a generic term that describes progressive cognitive and behavioural decline severe enough to interfere with daily life and independent function [4], and is a global health priority given its enormous human and economic costs.

Globally, the number of people with dementia (PWD) is increasing. According to the World Health Organization (WHO), there are approximately 50 million people with dementia, projected to reach 75 million by 2030 [4]. Studies indicate that women are more likely to develop dementia than men [5]. Furthermore, around 60% of PWD live in LMICs, which are aging rapidly and have limited capacity to support them [5]. In Peru, in 2022, the Ministry of Health (MoH) attended to 13,066 people with Alzheimer's Disease and other dementias [6].

Health systems in LMICs are not well equipped to address dementia, often resulting in inadequate or non-existent care. Specific challenges for the health systems and PWD include developing effective diagnostic services, managing cognitive and behavioural decline, handling multiple comorbidities, caregiver burden, widespread stigma, and lack of awareness about dementia. The concept of tracer conditions can help facilitate understanding the complexity of health systems and the challenges LMICs face [7,8]. Using tracers in health systems research is based on the premise that focusing on carefully selected health problems allows for the identification of weaknesses within the system and facilitates more direct insight of its performance [7,8].

Dementia affects multiple aspects of individual and family well-being, serving as an indicator of multimorbidity in both PWD and their carers. PWD have twice the number of chronic physical and mental conditions compared to those without dementia [9,10]. Dementia shares risk factors with many other common chronic diseases, including health related behaviours (e.g., unhealthy diets, smoking, physical inactivity), as well as obesity, hypertension, diabetes, depression, and social isolation. Together, these factors account for 35% or more of the population attributable risk (proportion of new cases of dementia due to the noted exposures). In Latin America and the Caribbean, this percentage can reach 56%, due to a combination of cultural, political, and economic factors [11].

In a broader context, addressing dementia does not mean working with a disease in isolation but rather a broader set of system-wide responses, both within and outside healthcare delivery structures, which can in turn contribute to achieving global goals such as Universal Health Coverage and the Sustainable Development Goals (SDGs) [12–16]. Abundant literature has pointed out significant deficiencies in protection systems which are relevant for addressing dementia. In Peru, despite having a specific law that addresses dementia (Law N° 30795: Law for the Prevention and Treatment of Alzheimer's Disease and Other Dementias) [36], PWD are affected by the fragmented healthcare systems, shortage of human resources, limited specialised services, minimal or non-existent long-term care and a siloed approach to addressing diseases and health conditions.

In the vast majority of cases [15–19], support available for individuals with chronic conditions in Peru, including dementia, comes from family members, predominantly women [20], who commonly lack access to information and primary or specialized dementia care services. A study across various low- and middle-income countries identified high psychological stress and caregiver burden, particularly among female carers of people with dementia [21]. Studies, such as those by Papastavrou, recognize caregiving for PWD as highly stressful for families, potentially leading to depression, panic disorder, anxiety, or substance use like psychotropic drugs, alcohol, and nicotine.

This landscape highlights the urgent need for improved dementia diagnosis strategies in Peru, considering the unique challenges posed by limited resources, illiteracy rates, and caregiver burden. Task-shifting approaches recommended by the WHO could help bridge the gap in dementia care [4]. Additionally, addressing the social and economic impacts of dementia requires a multi-faceted approach, involving collaboration between healthcare providers, policymakers, and community organizations. To understand the potential for such improvements on dementia diagnosis and care in Peru, a thorough exploration is needed of the existing health system and the problems that PWD and their carers face in daily life from a multi stakeholder perspective. For these reasons, this study aims to understand the response of the Peruvian health system to PWD and their carers as well as to explore the experiences of PWD of receiving their diagnosis and management of this condition. The findings will be structured using the lens of quality of services.

Methods

Context

The IMPACT Salud research programme comprises four distinct work packages (see Table 1). The first work package, the focus of this manuscript, is a descriptive cross-sectional study that uses a mixed methods approach consisting of a health system assessment (HSA) and an exploration of the patient journey. The HSA explores the response of the health system to PWD and their carers as well as the readiness of the Peruvian health system to implement new tools for diagnosis and management of dementia. This HSA involves diverse stakeholders and institutions including not only health services provision, e.g. civil society, municipalities, between others. The exploration of the patient journey through diagnosis, management and care of dementia will complement the information gathered from the HSA from a more centered perspective of PWD and their carers. The insights into the experiences of both PWD and carers within the health system will inform the development of a journey map which visualizes these experiences. The findings from the HSA and patient journey will inform other work packages of the programme and will allow for the identification of opportunities for improvements and intervention.

Setting

Study Regions

The IMPACT Salud programme is working across four sites in Peru (see Table 2). These include Lima, the nation's capital with over 10 million inhabitants [24], situated along the central coast. Lima holds significant importance as the country's primary city, burdened with the highest incidence of non-communicable diseases [25]. Notable for its social disparity and cultural heterogeneity, Lima is a dynamic research locale. The second city, Huancayo, has over half a million residents [26] and is

positioned in the central highlands at an elevation of 3200 meters above the sea level. A pivotal hub for the economic growth of the central region, Huancayo attracts migrants from the jungle and southern highlands, primarily engaged in providing diverse services for citizens and agricultural activities. The third city, Iquitos, serves as the primary urban center in the jungle, hosting almost half a million inhabitants [27]. Characterized by diverse indigenous populations, Iquitos can only be accessed via river and air transport, resulting in an economy marked by high transportation costs. Lastly, Tumbes, located in Peru's northern most region with 265,844 residents [28], operates as a border economy due to its proximity to Ecuador. With a warm, rainy climate, Tumbes is currently experiencing heavy rainfall attributed to "El Niño-Southern Oscilation (ENSO)" climatic phenomenon.

Healthcare System

The Peruvian healthcare system is fragmented and complex, with healthcare provision and financing depending on multiple public and private entities under the oversight of the Ministry of Health (MoH). Within this fragmentation, the two main public healthcare providers are the MoH and the Social Security System (EsSalud), depending on the Ministry of Labour and Employment Promotion [29].

This study will primarily work with the MoH, which serves 74.5% of the population [27]. Since 2007, there has been a coordinated and decentralized health system [31], which has resulted in the creation of regional health directorates and management for each region that, independently, are responsible for implementing MoH's regulations.

For the purpose of this research, we categorize the health system into three levels: micro, meso, and macro. The micro level encompasses primary health care services, along with any supplementary systems or organizations at the local level. The meso level includes secondary health care services and regional directorates. Finally, the macro level encompasses tertiary health care services, national directorates of the Ministry of Health, and specialized bodies.

Study objectives

The two parallel sub-studies have the following objectives. The HSA aims to [1] understand the needs of and resources available for PWD/carer dyads, and [2] assess the readiness of the Peruvian health system to implement innovative mobile health [mHealth] tools for the screening/diagnosis of dementia, and an intervention for PWD and their carers. The patient journey aims to [1] understand the journey of PWD to being diagnosed and receiving management for dementia, and [2] identify opportunities to improve the diagnosis and management of dementia for PWD.

Design

The HSA follows a Rapid Assessment Protocol (RAPIA) methodology for data collection, targeting access to care for individuals with chronic diseases in LMICs [32]. This approach leverages both primary and secondary data sources, interviewing participants across various competency levels, and operating within the four representative sites. Key attributes of this methodology include its patient-centric focus, cost-effectiveness, and provision of valuable insights for decision-makers. The rapid assessment methodology is implemented via structured interviews following a standardised questionnaire, supplemented with a review of secondary sources of information (e.g. policies and national statistics), to explore 11 themes related to the Peruvian health system across the three levels of the health system (macro, meso and micro). The patient journey utilizes in-depth

qualitative interviews with PWD, their carers and healthcare workers to explore the experience of receiving and providing diagnosis and management of dementia.

Participants and Selection Criteria

Table 3 details the different types of participants across the two sub-studies and the criteria used for purposive selection of participants. In the HSA, 14 types of key actors are participating, across the macro [4], meso [3], and micro [7] levels. The patient journey involves 3 types of key actors, PWD, their carers and healthcare workers. The aim is to achieve a comprehensive coverage of healthcare system stakeholders pertinent to the theme of dementia.

Sampling method

Across the HSA and patient journey sub-studies we aim to include 190 participants in total across the 4 sites through purposive sampling. The target sample size is detailed in Table 4. These numbers will allow for gathering sufficient information from all regions to understand differences across the four settings and levels. For recruitment of people with dementia there are specific inclusion criteria related to the stage of dementia and level of functionality. A community mapping exercise was conducted in each region to identify potential participants.

Fieldwork Team

Field workers in each site were selected for their expertise in conducting qualitative interviews, their healthcare sector experience, and residency in the designated city of work. A total of 10 field workers have been engaged, with 9 assigned to micro and meso-level interviews and 2 for the macro-level. A dedicated team of two or three researchers has been formed for each site, alongside a coordinator. Fieldwork team members attended two comprehensive training sessions, combining in-person and virtual formats. Training topics encompassed participant recruitment protocols, ethical considerations in elderly populations and dementia care, implementation of informed consent and assent procedures, an introduction to dementia from biomedical perspectives, and familiarization with the data collection materials. Upon completion of training, field workers received an operational manual detailing standardised operating procedures for data collection.

Data Collection Procedures

The study received institutional support from MoH and follows a staggered data collection approach. The process commences with higher management levels, progressively authorizing interviews at operational tiers such as first-level health centers. Identification of persons with dementia (diagnosed by a health center) and their carers is facilitated through community health agents, healthcare center workers, and healthcare facility administrations. They introduce the fieldwork staff, who then administer the Pfeffer Functional Activities Questionnaire (FAQ) [33,34] to assess PWD's functional abilities for daily activities and their possibility to participate in the interview. Scores below 6, indicating no clear impairment of functional activities, prompt interviews with both the caregiver and the person with dementia. In such cases, an informed assent is sought from the person with dementia, with informed consent obtained from the carer in their representative capacity. Figure 1 details the procedure for conducting interviews with PWD. For other actors, specific informed consent procedures are followed prior to initiating data collection.

For the HSA, interview information will be recorded in notes on a printed version of the interview questionnaire and captured with handheld recorders. These notes will then be entered into the

REDCap software. In this case, interviews will not be transcribed; only the recordings will be used as backup. This is due to the format of the RAPIA methodology, which advocates for a rapid analysis of information, prioritizing the perspectives of various actors rather than delving deeply into them, hence a detailed analysis of the testimony is not necessary. On the other hand, for the patient journey, the interviews will be recorded and subsequently transcribed verbatim and coded in an Excel spreadsheet. Following coding, the information will be shared in order to seek its validation at a meeting with PWD and careers who were interviewed.

Data Collection Materials

Questionnaires with closed and open-ended questions will be used to perform the structured interviews conducted in the HSA. These instruments were originally designed to assess health systems with regard access to insulin [35)], subsequently they had been applied for exploring chronic diseases and neglected tropical diseases [1]. Drawing from these previous experiences, they have been adapted for exploring several key thematic areas to assess the readiness of the Peruvian health system for diagnosing and managing dementia. These thematic areas are informed by the RAPIA guidelines mentioned above and are outlined in more detail in Table 5 including sections and topics of the structured interview questionnaire.

In the patient journey, we will employ interview guidelines for the in-depth interviews with PWD, carers and healthcare workers. The guidelines will explore topics to understand the diagnosis and management process of dementia and identify opportunities for improvement. Among the issues to be explored are the following: number of activities before the diagnosis of dementia, time between activities, number of interactions with health workers before diagnosis, number of interactions with health workers per year once the diagnosis is received.

Analysis Procedure

Three distinct approaches will be employed for data analysis. Firstly, analysis will address information pertinent to other IMPACT Salud programme work packages. Descriptive reports summarizing key findings on required topics will be prepared for each work package team. Secondly, the High-quality Health System Framework developed by Kruk et al. will be utilized to assess healthcare system readiness in dementia care [2]. This analysis will draw upon data from both the health system assessment and patient journey interviews. Lastly, following the example of a study on post-stroke care management [37], based on the patient journey interviews, a patient journey map will be developed to visualize the experience of PWD, carers and healthcare workers within the healthcare system. The interview data will be organized into pre-designed and newly identified codes using a matrix in Microsoft Excel, after which key milestones will be identified as significant in the patient's experience, as well as those identified by their carers and healthcare workers. The codes and journey map will be finalized in collaboration with patients and carers who participated in the interviews. The High-quality Health System Framework was designed to take into account the challenges of LMIC's and allows for a comprehensive evaluation of service quality beyond mere access, emphasizing patient-centered care and trust in healthcare systems. The Framework will allow us to organize and structure the results of our sub-studies in order to create an overall overview of the health system and the quality of services provided to PWD and their carers. The relevance of using this framework lies in its ability to integrate general aspects, such as access to healthcare centers and the number of consultations, with the patient's perception of the service's utility when describing service quality.

Ethical considerations

The research protocol, data collection materials and consent forms have been reviewed and approved by Institutional Review Boards at Universidad Peruana Cayetano Heredia and Imperial College Research Ethics Committee (ICREC). The study will be conducted in accordance with the recommendations for physicians involved in research on human subjects adopted by the 18th World Medical Assembly, Helsinki 1964 and later revisions.

Participation in the interviews will be completely voluntary, potential participants will be provided with information about what taking part will involve and signed consent will be sought for each participant prior to collecting any data.

In addition to the considerations mentioned above, specific measures to ensure ethical safeguards and to abide by local legislation will be taken in the cases of PWD and their carers. Assent and dissent will be respected from a PWD, verbally or non-verbally. Also, carers that function as proxydecision makers will be also consulted about consent when the potential participant hasn't been able to give full consent.

Results

The IMPACT Salud programme was funded on October of 2022 but the study was launched in Peru in November 2023, in the meantime, ethical approval and pilots were conducted before the implementation of both sub-studies. The pilot study took place from July to September 2023. The implementation of both sub-studies began in March 2024 and will extend until July of the same year. As of April 9, 2024, 30 individuals have been interviewed as part of the HSA from the cities of Iquitos, Huancayo, and Lima. Transcription and data systematization in REDCap will occur simultaneously with the administration of questionnaires and interviews. The analysis phase is scheduled to take place from July to December 2024.

Discussion

This work aims to serve as the foundational step in a series of studies across low- and middle-income countries, particularly in Latin America, assessing healthcare system readiness to effectively diagnose, manage and provide care for people experiencing dementia and chronic co-morbidities. As the burden of dementia and associated conditions rises among older populations in LMICs [38-40], there is a dearth of data on healthcare system preparedness.

The RAPIA methodology offers a diverse, multi-level, and national perspective to assess the health system, in this case having dementia as a tracer condition in Peru. While the patient journey compliments this by providing insights from a patient centered perspective about the healthcare system functionality. The HSA and the patient journey provide a comprehensive approach to understand how the health system and other services provide care for PWD and their carers, and leverages both primary and secondary data sources, through interviews of different stakeholders at the macro, meso and micro level.

The High-Quality Health System Framework will enable the analysis to be organized to identify structural issues (such as access, political support, and availability of qualified healthcare personnel), as well as relative or subjective issues contingent upon each dementia patient, caregiver, and healthcare provider (such as trust and service quality).

The decision to use a combination of methodological approaches is based on their focus on the end

user of the health system, namely persons with dementia (PWD) and their carers. Furthermore, the RAPIA methodology has the quality of being flexible to the context, allowing the addition of topics to the interview and new questions to the questionnaire [32]. Finally, the methods offer replicability benefits for researchers and health system specialists in terms of time and costs to implement.

The approach proposed in this study involves examining the macro view while also taking into account the daily lives of people living with dementia. By staying focused on these, we aim to propose solutions in the health system that have a tangible impact on people's lives. The study is including four sites with diverse characteristics in terms of population size, ecosystem, mother tongue, and number of people with dementia attended by MINSA, this will allow to compare the quality of the health system, experiences of PWD and carers as well as opportunities in four highly diverse contexts within Peru. The analysis will also address the needs of other IMPACT Salud work packages (see Table 1). For work package 2 that is focused on dementia diagnosis, information related to mHealth and dementia screening will be provided; for work package 3 that will pilot an adapted intervention for dementia care, information will be provided about models for monitoring PWD and providing support to their carers [41]; and for work package 4 that will conduct an economic evaluation on dementia care. The outputs of these analyses will be delivered in the form of periodic reports to the other work packages.

The study is focusing on carers due to the significant impact of caring for a person with dementia on their mental health. Carers are four times more likely to experience depression and three times more likely to experience anxiety [42,43]. For these reasons it is important to explore the needs of carers and possible opportunities to better support them and reduce any burden they experience. The intervention that will be adapted [41] in work package 3 of the IMPACT Salud programme (Table 1) will have carers as its focus, aiming to provide guidance and tools with the aim of improving quality of life of PWD and the mental health and quality of life of their carers.

It is important to note that utilizing healthcare system evaluations from high-income nations for public health decisions in LMICs is cautioned against due to considerable disparities in home care systems, healthcare professional readiness, technology and infrastructure availability, and the political stability essential for sustained quality care. As such, this research endeavors to provide updated insights into the intricate workings of healthcare systems in Peru, potentially driving reforms in the healthcare sector. Furthermore, it aims to foster alignment among stakeholders and amplify the impact of reforms on dementia patients' lives. A notable antecedent is the STRIDE project (Mexico, Brazil, India, Indonesia, Jamaica, Kenya, and South Africa), which evaluated healthcare systems' responses to dementia patients in Mexico [44]. STRIDE is a project that, like IMPACT Salud, involves actors from civil society, such as the Alzheimer's Association of Mexico, its allied associations, and researchers. However, STRIDE does not directly include the participation of patients and carers as project participants, as its goal is to improve the implementation of public policies rather than gathering the needs and experiences of people with dementia in the healthcare system A comparative analysis of findings between these projects is planned, aiming to elucidate differences and similarities. The results of this research also aim to provide input for the development of Comprehensive Care Guidelines for individuals with Alzheimer's Disease and Other Dementias, a task that the MoH has pending since its proposal in the 2018 regulation of the Law for the Prevention and Treatment of Alzheimer's Disease and Other Dementias [45].

Acknowledgments

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Authors' Contributions

JH, MLP, CB, JJM and MGL worked in the first version of the protocol. FTS, MLP, JH, and DRV worked to prepared the first draft of the protol for publication. All authors reviewed the questionnaires for the health system assessment and the journey map as well as reviewed and approved the current protocol.

Data Availability

The data that will be collected and analyzed in this study will be available from the study investigators (MLP, JH, SCF and CB). This will be done on reasonable request following what participants authorized in the informed consent.

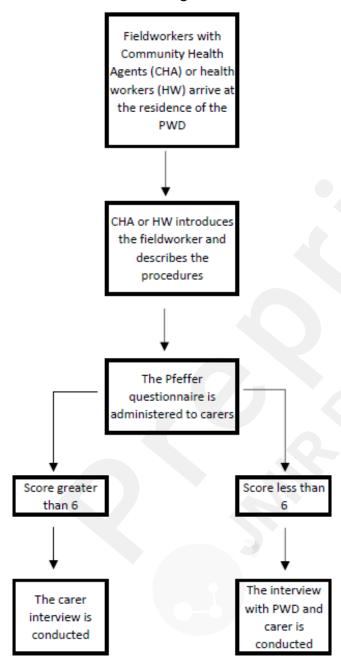
Conflicts of Interest

None declared.

Figures and tables

Figures

Figure 1. Procedure for conducting interviews with PWD



Tables

Table 1. Work Packages that conform IMPACT Salud

Work Packages	Objective
1	Evaluate health system readiness to diagnose, treat and support PWD and carers.
2	Develop and implement an mHealth-enabled system for diagnosis of dementia.
3	Determine the feasibility of an intervention to treat and support PWD and their carers.
4	Assess the economic burden of dementia and related co-morbidities in Peru and estimate the costs of rolling out the diagnosis tool at a national level

Table 2. Characteristics of the study sites/locations

Sites	Population	Region	Illiteracy rate in the department (15+)	Completed high school in the department (15+)	Most spoken language in the department	Quintile of dementia care in Peru
Lima (Metropolitana)	8,894,412	Coast	2%	50.2%	Spanish	1
Huancayo	545,615	Highlands (Andes)	5,3%	45.5%	Spanish	3
Iquitos - Maynas	149,773	Amazon Jungle	5.4%	50.1%	Spanish	1
Tumbes	2154 962	Coast	4.1%	48.3%	Spanish	4

Source: Instituto Nacional de Estadística e Informático (INEI)-2017 - Repositorio único Nacional de Información en Salud (REUNIS)

Table 3. Key actors and inclusion criteria

Sub stud	y 1	
Level	Target institution/key stakeholder	Inclusion criterio
	1) Ministry of Health (e.g. Mental Health Strategy, Non Communicable Diseases Strategy,	18 years of age or older
	Seguro Integral de Salud, Planning and resources)	Occupy the specified role in the Peruvian provinces of Lima,
	2) Ministry of Financing (e.g. Presupuesto por Resultados)	Huancayo, Iquitos, or Tumbes.
Macro	3) Seguro Social de Salud del Perú (EsSalud)	
	4) Ministry of Women and Vulnerable Populations	
	5) Key opinion leaders (e.g. Non-governmental Organizations representatives,	
	representatives of health organisations)	
	6) Regional Directorates of Health	18 years of age or older.
	7) Health Workers of Mental Health Public Hospitals, General Hospitals and Specialised	Occupy the specified role in the Peruvian provinces of Lima,
Meso	Memory Clinics (E.g. including psychologists and therapists)	Huancayo, Iquitos, or Tumbes.
	8) Nursing Homes run by District Municipalities	
Micro	9) Grass-root organisations and elderly community centers (Centro del Adulto Mayor)	18 years of age or older.
	10) Community leaders and community health workers	Occupy the specified role in the Peruvian provinces of Lima,
	11) Primary Healthcare workers (e.g. physician, nurses, technicians, pharmacies) from	Huancayo, Iquitos, or Tumbes.
	Primary Healthcare facilities and Community Primary Mental Healthcare facilities	
	(Centro de Salud Mental Comunitario)	
	12) PWD and Carers	Only for PWD:
		People with the diagnosis of dementia in a mild stage will be invited
		to participate. In order to select these participants, we will use:
		- Status of dementia: People will be asked for a self-reported
		diagnosis of dementia. In those cases where this is not possible the

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	carers will be asked about it. This diagnosis had to be performed by
	a physician in a health facility.
	- Level of functionality: The Pfeffer Functional Activities
	Questionnaire (PFAQ), spanish version will be applied to potential
	participants (31). The questionnaire includes 11 items with a likert
	score (0-4) with a total of 33 points. More than 6 points is
	considered a moderate-severe level of cognitive impairment that
	affects the functionality of daily life activities.
	- Also, we will include PWD that additionally have at least a chronic
	comorbidity such as hypertension, diabetes, depression, anxiety,
	among others.
	Carers: People that can be formal or informal carers including family
	members that are responsible for taking care of the PWD. They have
	been with the PWD in the process of diagnosis and management
	and are self-recognized as carers of the PWD. We will also include
	carers of people with severe stages with dementia.
Cub study 2	
Sub study 2	18 years of age or older
PWD	PWD: same as sub study 1
Carers	Carers:same as sub study 1
Health workers	Health workers: We will include general health practitioners and
	neurologists

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Table 4. Sample size

		Huancayo	Iquitos	Lima	Tumbes	TOTAL
Sub-study 1	Macro			10		10
	Meso	15	15	15	15	60
	Micro	20	20	20	20	80
Sub-study 2	PWD/Carers	6	6	6	6	24
	Healthcare workers	4	4	4	4	16

PWD: People living with dementia.

Type of data	Components	
General information		
	- Place and date	
	- Contact information	
	- Demographic information	
	- Workplace and time	
	- Occupational category	
Health system structure and		
	- Units or departments responsible for PWD	
	- Preparation of health personnel	
	- Preparation to attend comorbidities	
	- Services and organizations centred in PWD	
Relevant policies		
	- Public policies and relevant policies for PWD	
Financial issues		
	- Sufficient funding for prevention, diagnosis, and treatment in PWD	
	- Barriers or difficulties for find funding for PWD	
5 (11 () 11 ()	- Programs or financial contributions for PWD and careers	
Data collection and informa	ation systems - Date registration for PWD	
	- Statistic information available about PWD and comorbidities	
Service delivery in preventi		
	- Knowledge of the available tests for PWD	
	- Medications for PWD	
	- Peruvian political medication for PWD	
	- Knowledge of the available medication for PWD	
	- Barriers or difficulties in the access of medication, tests and technology for PWD	
Barriers for diagnosis	Current haviore to domantia accessor	
	Current barriers to dementia assessmentCurrent barriers to dementia attention	
	- Current barriers of dementia care	
Training/capacity to provid		
Training/capacity to provide	E CAIE	

Training, knowledge and capacity of healthcare workers in the provision/management of dementia care

Medical technology		
	-	Infrastructure to support internet access

- Infrastructure to support use of mHealth

Perceptions of and experience with using mHealth technology

- Knowledge of the tools for the dementia diagnosis
- Opinion about mobile applications for disease diagnosis

PWD: People living with dementia.

References

1. Cárdenas MK, Pérez-León S, Singh SB, Madede T, Munguambe S, Govo V, et al. Forty years after Alma-Ata: primary health-care preparedness for chronic diseases in Mozambique, Nepal and Peru. Glob Health Action. 2021 Jan 1;14(1):1975920.

- 2. Kruk ME, Gage AD, Arsenault C, Jordan K, Leslie HH, Roder-DeWan S, et al. High-quality health systems in the Sustainable Development Goals era: time for a revolution. The Lancet Global Health. 2018 Nov;6(11):e1196-252.
- 3. Hugo J, Ganguli M. Dementia and cognitive impairment: epidemiology, diagnosis, and treatment. Clin Geriatr Med. 2014 Aug;30(3):421-42.
- 4. Global action plan on the public health response to dementia 2017 2025 [Internet]. [cited 2024 Mar 25]. Available from: https://www.who.int/publications-detail-redirect/global-action-plan-on-the-public-health-response-to-dementia-2017---2025
- 5. World Alzheimer Report 2015, The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends.
- 6. Ministerio de Salud del Perú. Más de 9600 personas atendidas por alzheimer y otras demencias en lo que va del 2023. 2023 Sep 23; Available from: https://www.gob.pe/institucion/minsa/noticias/838671-mas-de-9600-personas-atendidas-por-alzheimer-y-otras-demencias-en-lo-que-va-del-2023
- 7. Calderon-Ticona JR, Taype-Rondan A, Villamonte G, Labán-Seminario LM, Helguero-Santín LM, Miranda JJ, et al. Diabetes care quality according to facility setting: A cross-sectional analysis in six Peruvian regions. Prim Care Diabetes. 2021 Jun;15(3):488–94.
- 8. Nolte E, Bain C, McKee M. Diabetes as a tracer condition in international benchmarking of health systems. Diabetes Care. 2006 May;29(5):1007–11.
- 9. Koyanagi A, Lara A, Stubbs B, Carvalho AF, Oh H, Stickley A, et al. Chronic Physical Conditions, Multimorbidity, and Mild Cognitive Impairment in Low- and Middle-Income Countries. Journal of the American Geriatrics Society. 2018;66(4):721–7.
- 10. Poblador-Plou B, Calderón-Larrañaga A, Marta-Moreno J, Hancco-Saavedra J, Sicras-Mainar A, Soljak M, et al. Comorbidity of dementia: a cross-sectional study of primary care older patients. BMC Psychiatry. 2014 Mar 20;14(1):84.
- 11. Parra MA, Baez S, Allegri R, Nitrini R, Lopera F, Slachevsky A, et al. Dementia in Latin America: Assessing the present and envisioning the future. Neurology. 2018 Jan 30;90(5):222–31.
- 12. Ghaffar A, Langlois EV, Rasanathan K, Peterson S, Adedokun L, Tran NT. Strengthening health systems through embedded research. Bull World Health

- Organ. 2017 Feb 1;95(2):87.
- 13. Hirschhorn LR, Langlois EV, Bitton A, Ghaffar A. What kind of evidence do we need to strengthen primary healthcare in the 21st century? BMJ Global Health. 2019 Aug 1;4(Suppl 8):e001668.
- 14. Saif-Ur-Rahman KM, Mamun R, Nowrin I, Hossain S, Islam K, Rumman T, et al. Primary healthcare policy and governance in low-income and middle-income countries: an evidence gap map. BMJ Global Health. 2019 Aug 1;4(Suppl 8):e001453.
- 15. GLOBAL SUSTAINABLE DEVELOPMENT REPORT. TIMES OF CRISIS, TIMES OF CHANGE: SCIENCE FOR ACCELERATING TRANSFORMATIONS TO SUSTAINABLE DEVELOPMENT [Internet]. 2023. Available from: https://sdgs.un.org/gsdr/gsdr2023
- 16. Malekpour S, Allen C, Sagar A, Scholz I, Persson Å, Miranda J, et al. What scientists need to do to accelerate progress on the SDGs. Nature. 2023;621(7978):250-4.
- 17. Magklara E, Stephan BCM, Robinson L. Current approaches to dementia screening and case finding in low- and middle-income countries: Research update and recommendations. Int J Geriatr Psychiatry. 2019 Jan;34(1):3–7.
- 18. Custodio N, Becerra-Becerra Y, Cruzado L, Castro-Suárez S, Montesinos R, Bardales Y, et al. Nivel de conocimientos sobre demencia frontotemporal en una muestra de médicos que evalúan regularmente a pacientes con demencia en Lima-Perú. Revista chilena de neuro-psiquiatría. 2018 Jun;56(2):77–88.
- 19. Dua T, Barbui C, Clark N, Fleischmann A, Poznyak V, van Ommeren M, et al. Evidence-based guidelines for mental, neurological, and substance use disorders in low- and middle-income countries: summary of WHO recommendations. PLoS Med. 2011 Nov;8(11):e1001122.
- 20. Walker R, Paddick SM. Dementia prevention in low-income and middle-income countries: a cautious step forward. The Lancet Global Health. 2019 May 1;7(5):e538-9.
- 21. Fam J, Mahendran R, Kua EH. Dementia care in low and middle-income countries. Curr Opin Psychiatry. 2019 Sep;32(5):461-4.
- 22. Bernabe-Ortiz A, Diez-Canseco F, Vásquez A, Miranda JJ. Disability, caregiver's dependency and patterns of access to rehabilitation care: results from a national representative study in Peru. Disabil Rehabil. 2016;38(6):582–8.
- 23. Prince M, Brodaty H, Uwakwe R, Acosta D, Ferri CP, Guerra M, et al. Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey. Int J Geriatr Psychiatry. 2012 Jul;27(7):670–82.
- 24. Instituto Nacional de Estadística e Informática (INEI). LIMA SUPERA LOS 10

- MILLONES DE HABITANTES AL AÑO 2022. Nota de Prensa Nº 006. 2022 Jan 17;1-2.
- 25. Venegas Ojeda D. Situación de las enfermedades crónicas no transmisibles: Problema cáncer. Plan de atención integral del cáncer Plan Esperanza [Internet]. Lima; Perú: Ministerio de Salud. Dirección General de Salud de las Personas; 2012 p. 1–81. Report No.: 1 ed. Available from: https://bvs.minsa.gob.pe/local/MINSA/2283.pdf
- 26. Viceministerio de Gobernanza Territorial. Información Territorial del Departamento de Junín del Perú [Internet]. 2019. Available from: https://cdn.www.gob.pe/uploads/document/file/1877542/Jun %C3%ADn_Informaci%C3%B3n%20Territorial%20Completo.pdf
- 27. Viceministerio de Gobernanza Territorial. Información Territorial del Departamento de Loreto del Perú [Internet]. 2019. Available from: https://cdn.www.gob.pe/uploads/document/file/1895090/Loreto_Informaci%C3%B3n%20Territorial%20Completo.pdf
- 28. Población Tumbes Población Tumbes Diresa Tumbes [Internet]. 2024 [cited 2024 Mar 25]. Available from: https://www.diresatumbes.gob.pe/index.php/estadisticas-de-salud/poblacion
- 29. Carrillo-Larco RM, Guzman-Vilca WC, Leon-Velarde F, Bernabe-Ortiz A, Jimenez MM, Penny ME, et al. Peru Progress in health and sciences in 200 years of independence. The Lancet Regional Health Americas. 2022 Mar 1;7:100148.
- 30. CEPLAN. Observatorio Nacional de Prospectiva [Internet]. [cited 2024 Mar 25]. Available from: https://observatorio.ceplan.gob.pe
- 31. Ministerio de Salud del Perú. Ley N.º 27813, Ley del Sistema Nacional Coordinado y Descentralizado de Salud [Internet]. Aug 12, 2002. Available from: https://www.gob.pe/institucion/minsa/normas-legales/254703-27813
- 32. Beran D, Higuchi, M. How to investigate access to care for chronic noncommunicable diseases in low- and middle-income countries. Draft for field testing [Internet]. 2012. Available from: https://www.access2insulin.org/uploads/4/9/1/0/4910107/who_ncd_manual_nov ember_2012_version.pdf
- 33. Pfeffer R, Kurosaki T, Harrach C, Filos S. Measurement of functional activities in older adults in the community. J Gerontology. 1982;37:323-9.
- 34. Pfeffer R, Kurosaki T, Chance J, Filos S, Beates D. Use of the mental function index in older adults: reliability, validity, and measurement of change over time. Am J Epidemiol. 1984;120:922–35.
- 35. Beran D, Yudkin J, de Courten M. Assessing health systems for type 1 diabetes in sub-Saharan Africa: developing a 'Rapid Assessment Protocol for Insulin Access'. BMC Health Serv Res [Internet]. 2006; Available from: doi: 10.1186/1472-6963-6-

- 17. PMID: 16504123
- 36. High-quality health systems in the Sustainable Development Goals era: time for a revolution The Lancet Global Health [Internet]. [cited 2024 Mar 25]. Available from: https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(18)30386-3/fulltext
- 37. Zafra-Tanaka J, Portocarrero J, Abanto C, Zunt J, Miranda J. Managing Post-Stroke Care During the COVID-19 Pandemic at a Tertiary Care Level Hospital in Peru. 2022;31(4):J Stroke Cerebrovasc Dis.
- 38. Walker R, Paddick SM. Dementia prevention in low-income and middle-income countries: a cautious step forward. The Lancet Global Health. 2019 May 1;7(5):e538-9.
- 39. Fam J, Mahendran R, Kua EH. Dementia care in low and middle-income countries. Curr Opin Psychiatry. 2019 Sep;32(5):461–4.
- 40. Sexton C, Snyder HM, Chandrasekaran L, Worley S, Carrillo MC. Expanding Representation of Low and Middle Income Countries in Global Dementia Research: Commentary From the Alzheimer's Association. Front Neurol [Internet]. 2021 Mar 15 [cited 2024 Mar 25];12. Available from: https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2021.6337 77/full
- 41. Possin K, Merrilees J, Dulaney S, Bonasera S, Chiong W. Effect of Collaborative Dementia Care via Telephone and Internet on Quality of Life, Caregiver Well-being, and Health Care Use: The Care Ecosystem Randomized Clinical Trial. JAMA Intern Med. 2019;179(12):1658-67.
- 42. Bao J, Chua KC, Prina M, Prince M. Multimorbidity and care dependence in older adults: a longitudinal analysis of findings from the 10/66 study. BMC Public Health. 2019 May 16;19(1):585.
- 43. El-Hayek YH, Wiley RE, Khoury CP, Daya RP, Ballard C, Evans AR, et al. Tip of the Iceberg: Assessing the Global Socioeconomic Costs of Alzheimer's Disease and Related Dementias and Strategic Implications for Stakeholders. J Alzheimers Dis. 2019;70(2):323-41.
- 44. López Ortega M, Astudillo García CI, Farrés R, Gutiérrez Robledo LM. Health and Social Care System Preparedness for Dementia Care in Mexico: Current Status and Recommendations to Achieve Optimal Care. Dementia (London). 2023 May 10;14713012231173806.
- 45. Congreso de la República. Ley N° 30795, LEY PARA LA PREVENCIÓN Y TRATAMIENTO DE LA ENFERMEDAD DE ALZHEIMER Y OTRAS DEMENCIAS [Internet]. Jun 18, 2018. Available from: https://busquedas.elperuano.pe/dispositivo/NL/1660608-13

Supplementary Files

Figures

Procedure for conducting interviews with PWD.

