

Equity and balance in applied dementia research: A Charter of Conduct and checklist for global collaborations

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Abstract

Introduction: Research capacity and capability for dementia in many low- and middle-income countries (LMIC) is still developing and often involves collaborations with high-income countries (HIC). Such collaborations may present equity risks and result in partnership imbalances. We developed a Charter of Conduct and researcher checklist to guide future international collaborations for dementia research.

Methods: Using modified consensus methods and case-based interactive and facilitated discussions, we developed the Charter with interdisciplinary dementia professionals and civil society members from the global South and North.

Results: Recommendations and a checklist for collaboration between researchers from LMIC and HIC include strategies to: (1) maximize power sharing; (2) ensure transparency; (3) consider equity and inclusion; (4) apply bidirectional learning; (5) build interdisciplinary dementia research capacity and capability; (6) develop long-term, sustainable collaborations, including members of civil society; and (7) align the work with local, national, and global health development goals.

Discussion: A Charter of Conduct, operationalised as a researcher checklist, will support international collaborations for dementia research, fostering an increase in dementia clinical research globally.

1.0 Introduction

With population ageing, the prevalence of dementia is increasing,¹ particularly in low- and middle-income countries (LMIC), where two-thirds of people with dementia (People with dementia) reside.² In many LMIC, health and social services for older people are scarce and the infrastructure to support People with dementia and their families is still developing. Likewise, capacity and capability for research related to non-communicable diseases (NCD), particularly dementia, is often limited.³ Barriers to developing dementia services and research are significant.⁴ The burden of home care is often placed on women, with direct and indirect personal, economic, and social impacts.⁵ Moreover, sociocultural and economic inequities, exaggerated by the COVID-19 pandemic, are important realities in LMIC.⁶

Dementia prevention and being able to 'live well' with dementia are imperatives that need to be addressed globally.⁷⁻⁸ Due to the cost and availability of resources, when disease-modifying therapies become more widely available, accessibility for most people in LMIC will be limited. Thus, local solutions focused on prevention and supporting quality of life must increase. Moreover, biotechnology and medication production already available in some LMIC should be leveraged to foster this effort.

There have been increasing calls for dementia research funding to consider longer-term and more equitable approaches.⁹ Specific 'roadmaps' for LMIC are emerging, providing a principle-based steer to develop applied dementia research capacity building, implementation science, and capability involving international partners.¹⁰⁻¹¹ However, developing equitable partnerships that build health research capacity in LMIC is complex due to existing inequalities upon which these partnerships are often based.

The purpose of this article is to report on a series of transnational workshops and consultations with dementia-related researchers and non-governmental organisations (NGOs) exploring how international collaborations for dementia research between LMIC and high-income countries (HIC) can be conducted equitably. The specific aim was to co-develop a Charter of Conduct to guide future clinical dementia research collaborations, ensuring advancement of the field for the betterment of people at risk of or living with dementia, and their families.

2.0 Background

Historical context and rationale

Nature and risks of international research collaboration for dementia

Much has been written about LMIC-HIC collaborations in health, particularly related to global health academic partnerships (GHAPs). GHAPs include traineeships, medical missionary and volunteer programs, and are generally based on the model of HIC - with greater advantages and resources - contributing research, clinical expertise and funding to improve healthcare capacity and capability in LMIC.¹²⁻¹⁵ However, these collaborations often bring imbalances, with one partner leading and controlling funding, and the other partner being expected to comply.¹⁶⁻¹⁸ This opens the possibility of exploitation and disruption of local healthcare systems, unplanned shifts of the medical workforce, and medicalisation of deprivation.¹⁹⁻²¹

The current health sciences literature on LMIC-HIC collaborations predominantly relates to infectious diseases, rapidly remediated health issues, and post-crisis interventions. However, with the growing emphasis on NCD, consideration needs to be extended to dementia research. Working in partnership to mitigate the impact of dementia, which is partly related to ageing populations, increasing affluence and 'Westernised' lifestyles, requires enduring relationships among health professionals, often with goals based on outcomes that may be remote from the intervention. Furthermore, with growing global funding opportunities, easier means of transnational communications, and the diaspora of health professionals and investigators, HIC researchers are increasingly developing collaborations with LMIC partners, and vice-versa.

Examples of unbalanced 'collaboration' in dementia research

Emerging models for LMIC-HIC dementia research involving human participants often centre around clinical trials, where an intervention is developed in HIC and adapted to LMIC requirements; however, frequently, these interventions are simply "copied and pasted". HIC partners typically provide and manage the funds, project coordination, and, in many cases, the expertise and special resources not available in LMIC. LMIC, in turn, provide research participants, local research teams, and contextual knowledge. Governance, quality control, and due diligence requirements are often at the behest of HIC funders. The research agenda is usually dictated by HIC investigators, biasing the topics of interest, approaches, and interventions. Moreover, the lack of patient and public research involvement in most LMIC adds another barrier to the orientation of researchers towards the priorities of the indigenous population. These factors lead to neglect of specific scientific developments, local clinical and research agendas, and targeted LMIC-related needs. In addition, participants may be blind to the research agenda and the HIC role. More broadly, ethical, participant and data protection standards can vary among centres to the detriment of LMIC-based participants.

Similarly, grants tend to sustain inequalities through low costs for recruitment for LMIC, and increased costs for HIC activities. In some cases, it may be difficult for the LMIC partner to meet the study requirements, opening possibilities for strained relations or an undelivered project.

The consequences of these vertical relationships may range from outright exploitation and unethical practice, to subtle imbalances in decision-making, development of the study protocol, representation of the steering committee and other aspects of the project delivery. In the non-dementia literature, this has been broadly referred to as neo-colonialism, research imperialism, and specifically, in relation to HIC projects intended to provide aid to LMIC, charitable imperialism.²²⁻²⁴

To protect against negative and unintended consequences of LMIC-HIC collaborations, the ethical and philosophical frameworks within which such activity is being conducted need to be considered,²⁵⁻²⁷ particularly in view of the wider societal shift towards global responsibility and equity. Indeed, definitions of global health are starting to incorporate principles of equitable and bidirectional partnerships.²⁸

3 Approach to developing a Charter of Conduct

Several steps were undertaken to develop the Charter of Conduct (Figure 1).

3.1 Preparatory activity

We initially convened a Steering Group of four dementia healthcare professionals and investigators (IL, MG, PC and WK) with experience in LMIC-HIC partnerships and representing the global South/LMIC (PC, WK) and the global North/HIC (IL, MG). The steering group met virtually to establish the project's strategic framework and methods. This was achieved by an in-depth analysis of existing frameworks of research collaborations for relevance. Following the qualitative research model of Coughlan and Macredie,²⁹ an Expert Reference Group (ERG) was established, drawing on experts with consideration of regional (LMIC and HIC), discipline and career-stage diversity. We also strove to ensure different perspectives were represented across medical specialties, policy, clinical practice, research, and advocacy. Several ERG members belonged to existing dementia research consortia involving LMIC-HIC collaborations and were thus specifically invited to share their experiences, focusing on gaps and challenges. The ERG participated in a series of workshops structured around a model case study, including a modified SWOT analysis (Strengths, Weaknesses, Opportunities and Threats), that formed the basis of discussions in small groups.

3.2 Linkage to other global partnership frameworks

The Steering Group reviewed theoretical and philosophical frameworks related to global health partnerships to guide the approach. Selected frameworks were related to social justice principles, sustainability, and the nature of the partnership. They included: the UK Research Institute report, *Working in Effective Partnerships to Address Sustainable Development Goals*;³⁰ partnership principles outlined by the Tropical Health and Education Trust;³¹ partnership assessment tools from the Canadian Coalition for Global Health Research (CCGHR);³² and the Swiss Commission for Research Partnerships with Developing Countries (KPF)'*s Guide for Transboundary Research Partnerships*.³³

The Steering Group also drew upon guiding principles in the health sciences literature, including Paulo Freire's 1978 notion of 'authentic help'³⁴ and the social justice principle of equity related to gender, class, race, religion, access to services, professional and academic status, and discipline. We also examined the operations of the STRiDE project (*'Strengthening Response to Dementia in Developing Countries'*; www.Stride-dementia.org), a UK-funded targeted capacity development initiative taking place in seven LMIC, as an example of good practice regarding dementia researchers working closely with members of civic society. We shared these frameworks, principles, and exemplar of good practice with the ERG as a basis to align the themes that emerged from Workshops 1 ('problems', i.e., weakness and threats) and 2 ('solutions', i.e., opportunities and strengths), described below.

3.3 Participants and workshop logistics

Professional and academic experts (n=63) for the ERG were identified for their clinical, research, policy expertise, or personal experience in dementia. All had experience of LMIC-HIC collaborations. The ERG was purposefully balanced by gender, geographics, LMIC/HIC origin, profession, career-stage and type of working environment. Representation was from 26 countries, of which 35 experts (56%) were based in LMIC and 28 (44%) in HIC, including 29 members of the Global Brain Health Institute (www.gbhi.org) with extensive experience of working collaboratively across LMIC and HIC. Members of the GBHI community were based in Dublin, Ireland or San Francisco, USA (faculty and current fellows), or globally (senior fellows). Experts represented the following domains: clinical specialties (n=22); social science/policy/health economics (n=11); public health/epidemiology (n=6); biomedical/cognitive sciences (n=14), arts/humanities (n=4), business/technology (n=4); and advocacy (n=2).

Experts attended face-to-face or online workshops, with each of two workshops being held multiple times to accommodate diverse time zones. Background reading material and a model case study were provided to experts prior to the meetings. The case illustrated a LMIC-HIC multi-centred

randomized controlled trial evaluating the impact of a complex intervention on dementia-related outcomes. The funding, chief investigator, research protocol, and trial management team members were from the HIC. The principal investigators and site study staff were based in the LMIC. Data analysis and dissemination of results were driven by the HIC-based partners.

Workshop 1, conducted face-to-face and remotely in Dublin and in San Francisco, elicited views and experiences of LMIC-HIC collaborations for dementia research, focusing on issues of equity, balance, and risks of exploitation, triggered by the case study. Each workshop had a lead facilitator introducing the topic and providing a point of reference for the guided discussion in breakout groups, facilitated by domain experts. Facilitators prompted discussion and invited ERG contributors to discuss challenges and gaps they had experienced in their collaborations involving LMIC and HIC researchers. Next, a guided a modified SWOT analysis was undertaken by posing a series of key questions relevant to the objectives. Any examples of tacit knowledge were probed. Facilitators and scribes captured all outputs.

Workshop 2, conducted eight months later explored potential solutions for the case study from Workshop 1, forming the basis of a draft 'Charter of Conduct'. Following the workshops, findings were analysed for thematic content and matched against the agreed-upon principles to create a draft Charter of Conduct based on seven key recommendations that could be operationalised in real world settings relevant to dementia work.

3.4 Key opinion leaders (KOLs) and civil society feedback

The draft charter was sent for critical feedback from international stakeholders, including members of civil society from third sector organisations supporting global dementia research such as Alzheimer's Disease International (ADI) and members of national Alzheimer's societies, such as Brazil, India, Jamaica, Kenya and Pakistan. ADI, as a global organisation, represents the views of both LMIC and HIC civic advocacy groups working to support people with dementia and their families. Feedback received was incorporated into the final Charter draft. Feedback included: aligning the research with local/regional/national health strategies; highlighting the shift of HIC partners from front-line to advisory roles; including research funds to support capacity and capability development; and focusing more on inclusion of underrepresented groups of researchers and participants. Additional feedback from civil society members included: modifying the language; including patient and public

involvement' (PPI) in developing and conducting clinical dementia research; and involving advocacy groups and civic organisations in the work.

3.5 Development and field test of the checklist

From the modified Charter with the seven recommendations, we were able to derive a 27-item checklist, the '*Balanced Partnership for Dementia Research Checklist*' to assist clinical researchers in the field implement the recommendations and monitor adherence to the recommendations throughout the lifecycle of the collaboration. Each recommendation was operationalised by one or more checklist question with outcomes as 'yes', 'no' or 'somewhat' (scored 2.0, 0 or 1.0 points; total maximal score = 54; higher score representing a more balanced partnership) for ease of use. The checklist is intended as focus for discussion among collaborators regarding adherence to the Charter principles, rather than scale with a definitive cut-point or formal psychometric properties. The checklist can be used at the start of a collaboration and revisited annually, or at key milestones throughout the life of the project.

To test the utility of the checklist, we applied it to two existing LMIC-HIC dementia research collaborations, the SENSE-Cog Asia project,³⁵ which is adapting a sensory support intervention for people with dementia living at home in three South Asian countries (Bangladesh, India and Pakistan) in collaboration with UK investigators, and a data-mining collaborative study on Theory of Mind in Alzheimer disease, conducted between colleagues in Brazil and France.³⁶

4.0 Results

4.1 Themes emerging from Workshop 1

Based on the case analysis in Workshop 1, the ERG outlined several equity-related issues at each step of the research process, from the outset of the study question being posed and the funding being obtained, to the final point of dissemination of results. These were conceptualised as 'threats (T) and weaknesses (W)' of the SWOT analysis, including items related to the case as well as from experts' own experiences (Table 1).

4.2 Themes emerging from Workshop 2

In Workshop 2, using the same case study, the ERG focused on solutions to the issues raised in Workshop 1, which were conceptualised as the 'opportunities (O) and strengths (S)' domains of the SWOT (Table 1).

[insert Table 1 here please]

4.3 Alignment of themes with principles for the draft Charter of Conduct

The themes extracted from the SWOT conducted in Workshops 1 and 2 were aligned with the key principles derived from the literature, as described above, forming the basis of a draft charter with the following seven recommendations:

(1) Maximize power sharing at each stage, ensuring fairness among partners. Applied dementia research is interdisciplinary, dependent upon a blend of skills. An ideal collaboration requires that all members are empowered, autonomous, and able to contribute meaningfully, based on principles of co-creation and participation.³⁷ Thus, dementia research collaborations should reflect a balance of power across parties, between and within medical and non-medical disciplines, with each team member adopting a non-paternalistic, de-centred stance. Inclusion of members representing the interests of people with dementia and their families should be prioritized.

Power imbalances can manifest in multiple forms during collaborative projects. However, this can be obviated by embedding the principle of co-creation from the outset of the collaboration and identifying opportunities for reciprocity among team members, including defining the study question, goals and hypotheses, developing the protocol and undertaking operational aspects. Often, disproportionate time and effort may be spent satisfying requirements of HIC, and the efforts of the LMIC partner are sometimes rendered invisible, since the obstacles and difficulties are not factored into the process. Finally, study finances, outputs (authorship, credit-sharing, attributions), and data (data sharing, storage, ownership), should be distributed fairly, and explicitly agreed upon at the outset.

(2) Ensure transparency, openness and enabling conversations among team members. Addressing expectations and assumptions openly from the outset of the collaboration can contribute to mutual trust and respect, essential for a successful and enduring collaboration. Differences in communication style, language, culture, as well as subtle issues such as time management and perceived hierarchical relationships, often represent challenges in international collaborations. Promoting openness and transparency regarding these issues, as well as clearly articulating the roles,

responsibilities and accountability of each team member is essential to avoid misunderstandings. This also fosters efficient and sustainable working relationships. The potential impact of the work on local teams (i.e., costs, reallocation of the existing workforce, task shifting) should be made clear at the outset. Direct costs are often substantially lower in LMIC, necessitating efforts to actively avoid unequal budget distributions by promoting increased funding for more balanced capacity building and administrative and financial support of LMIC teams. Moreover, researchers should be explicit about their motivations for working together, as these often differ markedly between LMIC and HIC staff and may shift over time.

(3) Consider equity and inclusion among partners, guided by social justice principles. International research partnerships for dementia must resolve the tension between addressing a gap in services and knowledge in low resource settings, and perpetuating the power imbalances and inequities that often played a part in producing the gaps. Hence, it is important to incorporate social justice and equity perspectives that address gender, socioeconomic, religious, racial, and other inequalities. LMIC health systems often have vertical and gender-based power structures, which may be mirrored by the research team. Furthermore, racial, cultural, ethnic, or other inequities, often explicitly addressed in many HIC institutions under 'Diversity, Inclusion and Equity' policies, are often not prioritized in LMIC institutions. Thus, while the focus of this Charter of Conduct is largely on the relationship among international partners of the research consortium, practices and approaches *within* the respective teams should also be considered.

Inequities in education, training, background, and professional status, are also important to consider, particularly in more patriarchal systems. This is essential in applied dementia research where a multidisciplinary approach is required. The healthcare workforce for dementia research in most LMIC is limited and frequently depends on task-sharing with non-specialists in community settings. Non-specialists are often female, non-medically trained and poorly remunerated.³⁸ Education and training inequities can also be addressed under the principle of capability and capacity-building (recommendation six below). Additionally, less apparent sources of professional inequity within the team arising from the prohibitive cost of international travel, lack of research time, less administrative support, and the lack of prioritization of research, need to be considered. Finally, while there is an overwhelming emphasis on publishing findings in English in internationally recognised journals, such practices often exclude LMIC researchers, both from publication, as well as accessing outputs. This can be obviated by supporting local or national journals and including these in dissemination plans.

(4) Aim for mutual and bidirectional learning and growth. Global health partnerships increasingly focus on meaningful two-way exchanges of knowledge and expertise, which should be incorporated into any dementia research collaboration. This builds on the assumption that partners can make equal and complementary contributions, creating equal spaces for knowledge generation and reflecting a willingness to learn from each other's local communities. This approach intentionally addresses the risk of HIC partners taking on the role of 'research saviour', and instead, adopting a stance of cultural humility devoid of assumptions.

As awareness and services for older adults, particularly those with dementia, develop in many LMIC, learning from LMIC-partners can resonate significantly in HIC. Notably, translated and culturally adapted tools and assessment approaches in LMIC settings can inform approaches for dementia management and support with migrant communities in HIC. Furthermore, LMIC-based research into cost-effective approaches for dementia can inform better approaches in HIC, where budgets pressures also exist.

Finally, all partners of the collaboration must strive for bilateral 'cultural competence'. While not always practicable nor affordable, particularly in LMIC, attempts should be made to visit and spend time in each other's countries/institutions to deepen understanding and develop appreciation of overt and implicit working aspects. This entails building in time and budget for researcher exchanges during the project, as well as meaningful exchanges and open dialogue with the PPI team members.

(5) Build capacity and capability for interdisciplinary dementia research, including role modelling and peer support. Since dementia research in many LMIC is still evolving, new project proposals should include capacity and capability building in the project plan, with the goal of eradicating inequities in resources, knowledge, skills, and service provision, leading to tangible and sustainable outcomes.⁴ Examples of research methods and service delivery training in LMIC for NCD already exist and could provide models for dementia research.³⁹

Capacity and capability building should have allocated funds, clear protocols and reporting of outcomes supported by change mechanisms such as Theory of Change (ToC).⁴⁰ ToC provides a detailed description of how and why an expected change may occur in a certain context and sets out milestones leading to desired and adjustable goals based on a shared vision, such as improving the lives of people at risk of or with dementia, and their families.

(6) Develop long-term collaborations for sustainability of the work and outputs. Due to the enduring nature of dementia, the focus of international collaborations should be on cultivating medium- and long-term relationships between individuals, groups and institutions, with a conscious goal of breaking down silos and ‘empire-building’ that limit equitable partnerships. Teams should guard against research where the traditional academic outputs are prioritized over sustainable services and implementation, and instead focus on longer-term solutions that fit in with local health and socioeconomic priorities.

In global clinical partnerships, capacity building is shifting from HIC partners being at the front-line providing care to now taking on an advisory role.⁴¹ Similarly, the goal for international dementia research collaborations should focus on local capacity and capability building, embedding civic organisations such local Alzheimer’s society chapters, exemplified by STRiDE. This approach signals the eventual shift to HIC partners acting as supportive consultants to an already expert team.

(7) Align the work of the partnership with local/regional/national goals for health systems. The focus of dementia collaborations should be on impact and should attempt to avoid vertical and ‘quick fix’ approaches based on narrow biomedical models of disease that do not consider the social, cultural, and political contexts for the manifestation of the condition.⁴² However, due to the developing nature of dementia services in many LMIC, local policy may not yet be articulated and national policy may not yet include older adult health, including dementia.^{10,38}

In some LMIC, unstable economic development, significant economic disparities, formal care scarcity, and fragile and/or fragmented health systems, coupled with a disproportionate impact of COVID-19, has demanded novel local-global actions. Brain health diplomacy (BHD), which incorporates clinical dementia research and convergence science⁴³ can provide an innovative framework to develop multidisciplinary initiatives in the context of LMIC inequalities, based on integration of knowledge, tools and actions developed at the interface of the fields involved in dementia research. Compared with classical isolated approaches to research, BHD can articulate multisectoral actions by developing integrated strategies that directly tackle HIC-LMIC inequalities.⁴³ Organizations like GBHI, and projects such as STRiDE, are pioneering convergent frameworks favouring triangulation among global funding, local emergent professional and lay leaders, and collaborative models.

Finally, to ensure the meaningfulness of the research agenda, PPI and civic society engagement through NGOs should be built into any applied dementia research program. In dementia research, PPI ensures that the perspectives of those with “lived experience” of dementia are considered. To

date, in many LMIC, with a few notable exceptions (i.e. Miah et al.⁴⁴; Breuer et al.⁴⁵), PPI is not well-known nor regularly undertaken. PPI in LMIC can play a pivotal role in cultural adaptation of interventions, ensuring relevance and fostering future implementation of positive findings, as well as dissemination.

[Insert Table 2 here please]

Checklist for researchers

The '*Balanced Partnership for Dementia Research Checklist*' (Table 3), when applied to the two dementia studies^{35,36} revealed scores of 18 out of a total score of 27 (66% of the total score) and 16 out of a total score of 22 (5 'not applicable' items, thus the total score was lower; 72% of the total score), respectively, where a higher score is better. The higher percentage score attained by the Brazil-France study reflects a greater maturity of the collaboration achieved over time and greater awareness of the recommendations outlined in our Charter of Conduct. Table 3 shows the items endorsed by each team at study conclusion. The checklist was not available at the baseline points of the respective studies.

[insert Table 3 here please]

5.0 Discussion

Here, we have proposed a framework and checklist to guide international collaborations for dementia research, underpinned by principles based on equity, fairness, and balance. Our recommendations derive from the global health literature combined with domain-specific expert consensus opinion, representing the multidisciplinary nature of the field. We have attempted to operationalise the principles with an aim towards pragmatic application by research collaborations working to improve the lives of people with dementia and their families in LMIC. Our framework and checklist underscore the importance of capacity and capability building aligned with existing local and national priorities regarding aging and health, and with a view to enhancing the bidirectionality of the flow of knowledge. We argue that all partnerships should agree on a model of what an optimal collaboration entails, and aspire to achieve this at the outset, with transparent processes, including a Memorandum of Understanding, if needed.

In recent years, recognition of the importance of fostering equitable partnerships in global health has led to the emergence of reports, guidelines and frameworks to support more ethical and equitable LMIC-HIC partnerships. Formulated by a range of actors and institutions, the literature on equitable GHAPs is diverse, and the ethical issues addressed, wide-ranging.⁴⁶⁻⁵¹ At one end of the spectrum are guidelines focused on reducing outright exploitation and unethical research practices, such as ‘ethics dumping’ scenarios in which HIC teams locate their studies in LMIC with the intent of taking advantage of less rigorous research governance structures⁴⁷ and ‘job and run’ studies that provide scientific advancement at the expense of participants and LMIC health systems and perpetuate colonialist attitudes. On the other end of the spectrum are guidelines focused on more nuanced, but common, issues that may arise in relation to GHAPs. These highlight the tendency for unbalanced partnerships to lead to unethical practices which are perhaps less apparent than overtly exploitative scenarios. Guidelines, such as those from Larkan et al.,⁴⁶ highlight strategies for critically assessing partnership formation and implementation, with a focus on representation, local benefit, cultural awareness, and sustainability.^{46,48}

A framework specific to dementia research partnerships is of critical importance for several reasons. Chief among these is that dementia partnerships present unique challenges. Existing capacity for research and service provision in dementia is relatively limited in many LMIC, an important gap that is increasingly filled through collaborations incentivised by HIC and global funding bodies. The rapid growth in the number of studies addressing dementia in LMIC, as exemplified by a recent special collection (<https://www.frontiersin.org/research-topics/12753/dementia-in-low-and-middle-income-countries>), suggests an urgent need for dementia-specific guidelines. In addition, there are unique characteristics and challenges associated with the study and treatment of this condition. The non-linearity of cognitive decline, the presence of complex ethical considerations including informed consent processes, and the long-term nature of the condition, are examples of the unique challenges facing dementia research and service provision. As a result, we would argue that the metrics of success typically employed in infectious disease research have less relevance to the dementia field. For dementia, there are a few ‘hard’ outcomes, and the expression of the condition varies widely, often being closely tied to social, cultural, and familial contexts. Thus, we would argue that using the person-centred model for dementia care,⁵² embodying equity and balance, LMIC-HIC collaborations should also prioritize the person-centred approach.

Validation of the framework will be an important next step. Guidelines are not useful unless investigators can operationalise them ‘on the ground’. Thus, it will be important to test our checklist in various global settings. This will help ascertain the success of a collaboration, using our framework

as a benchmark. Roadmaps for development of LMIC clinical dementia research should include adoption of the framework (e.g., Leroi et al. 2019¹⁰). Empirical evidence on the application of the framework in future partnerships would allow the framework to be refined and updated.

6.0 Limitations

It can be argued that in resource-limited health systems for dementia care and low public awareness, the priority should be on service development rather than research. However, health research is concerned with discovering new information, fostering awareness and providing a solid evidence base can stimulate the development of services, care pathways, and policies. Ensuring that research is ethical, equitable and based on balanced partnerships is therefore fundamental. Clinical dementia research will be an indispensable foundation of economic, technological, and translational development of nations in the next decades.

We acknowledge the limitations of our ERG regarding regional and cultural representation. While we sought to achieve balance and wide-ranging representation, gaps persist. We recognise that a few representatives from large regions (e.g., Latin America) will not be able to reflect the rich diversity and cannot be expected to speak on behalf of all researchers from that region.

7.0 Conclusion

International partnerships in dementia research, if genuinely equitable, can engender progressive exchange and bidirectional innovation and learning, leading to important advances, including a reduction of the global burden of dementia. However, navigating these relationships can be challenging, and without careful consideration and true collaboration, partnerships will fail to optimise these important opportunities, which may be hampered by existing complexities such as coloniality and deep-rooted power structures.

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