



Capacity & capability building for applied dementia research in low- & middle-income countries: Two exemplars from South Asia

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Background & objectives: Cognitive and other neurodegenerative conditions related to ageing have become public health priorities in low- and middle-income countries. However, contextually based, applied research to support the development of awareness, diagnosis and care pathways for people with dementia in South Asia is still largely undeveloped. This study was aimed to use applied research studies for dementia in South Asia as exemplars of how individual-level capacity and capability building for dementia research can be achieved.

Methods: Using Theory of Change as a framework, we embedded capacity and capability building into the studies through six domains: people (human resources), research integrity and governance, study delivery skills, international collaborative working, patient and public involvement (PPI) (awareness raising, stigma and health literacy) and development of 'pathways'. For each aspect, development goals were defined and how they would be achieved.

Results: New principal investigators, research assistants (including outcome raters), study coordinators and intervention practitioners were trained across eight study sites in India, Pakistan, and Bangladesh, for dementia research. Training was delivered at study start, and through booster sessions, using workshops, face-to-face sessions, online training and video-link sessions. International collaborations were fostered, leading to a proposal for international funding. Each study site co-created PPI events to raise awareness and to inform the research. The recruitment pathways and study logistics fostered the development dementia diagnosis and care pathways.

Interpretation & conclusions: Embedding capacity and capability building in applied dementia research in South Asia fosters the sustainability of dementia research, which is essential in developing diagnostic and care pathways.

Key words Ageing - capacity and capability building - clinical trial - cognitive - dementia - non-pharmacological intervention - South Asia

Cognitive and other neurodegenerative conditions related to ageing have become public health priorities in low- and middle-income countries (LMIC)¹. Despite this, research to support the development of awareness, understanding, diagnosis, care and support for people with dementia (PwD) in South Asian countries is still largely undeveloped². Such research is essential to inform all aspects of the dementia health and social care spectrum, which must consider local and national micro-, meso- and macro-level contextual factors. Moreover, there is a dearth of health professionals in LMICs, who are able and willing to get involved in health sciences research with relevance to non-communicable diseases (NCDs)^{3,4}, particularly dementia and mental health.

In 2019, an international group of expert stakeholders interested in dementia research in South Asia co-developed a 'Roadmap for Dementia Research in Pakistan' as a model for LMICs². This initiative included a LMIC-relevant set of research priority topics, derived from the World Health Organization's (WHO) research priorities that arose from the 2013 G8 Dementia Summit, 'Global Action Against Dementia'⁵. The priority topics in the Roadmap included research to raise public awareness and understanding, prevent and reduce risk, improve the quality of life for PwD and their care partners and explore the most appropriate type and delivery of care and services. These topics arose from the current lack of awareness of dementia as a diagnosis and the stigma that continues to be associated with mental health conditions in South Asia^{6,7}. While the South Asian model of family-supported, home-based care may be a strength compared to many high-income countries (HIC), the lack of formal outside support can result in significant physical, mental and economic burdens on family members, particularly women, who are most often the primary caregivers. Other issues include the relative lack of cultural, education and language-appropriate assessment tools and care pathways for dementia⁶.

Another aspect of the 'Roadmap for Dementia Research' initiative was the establishment of principles, priorities and goals for dementia research². One of the 10 key principles proposed was the need to include capacity and capability building for dementia research embedded within, or running alongside, individual research projects and programmes. This is particularly the case for international research collaborations, where a HIC may be funding research in a LMIC, as a

first step in developing sustainability and independence of the LMIC research team in the longer term. With increased funding opportunities, easier means of communications across continents, cheaper travel and the global diaspora of health professionals, there are increasing opportunities for HIC-LMIC collaborations, particularly in the area of NCDs, such as dementia.

To date, only a handful of collaborations in which the primary aim has been capacity and capability development for applied dementia research in LMICs exist. These are called 'targeted capacity development' initiatives⁷. A notable example is the 'Strengthening Response to Dementia in Developing Countries' programme (STRiDE; www.Stride-dementia.org). STRiDE is a UK-funded initiative taking place in seven LMICs. The Global Brain Health Institute (www.gbhi.org) has been developed as a leadership training programme for brain health, jointly offered by Trinity College Dublin and the University of California, San Francisco, for mid-career professionals from diverse disciplines. In addition, the UK's Global Clinical Research Fund (GCRF) is funding a series of initiatives. These include a project to develop HIC-LMIC networks for early career dementia researchers between the UK and Brazil⁸ and a project testing the feasibility of a culturally adapted intervention for dementia. This latter project is an example of an 'integrated capacity development' initiative⁷.

The theoretical basis for the development of capacity has been described elsewhere⁹, but in the LMIC context, models of development tend to be directed at the institutional level¹⁰. In contrast, we focussed our efforts at the individual level, with knowledge, awareness and skills training at the core. Here, following the principles laid out in the 'Research Roadmap for Dementia'², we report on the integrated capacity and capability building aspects of two studies of applied dementia research in South Asia: the first is a multi-site feasibility study of a culturally adapted non-pharmacological intervention undertaken in Bangladesh, India and Pakistan (SENSE-Cog Asia) and the second is a single-site study of developing and implementing interventions for dementia in a rural community in India (RiDe). A modified case study approach was used to demonstrate how the capacity and capability building goals were met, ranging from training to awareness raising.

Material & Methods

To develop an integrated capacity and capability building strategy, the goals were established, embedded within a 'Theory of Change' framework¹¹, across the six domains (Table): people, research integrity and governance, study delivery skills, international collaborative working, PPI (including awareness raising, stigma and health literacy) and development of 'pathways' (logistics, referrals, links to existing or developing services). These domains were agreed with the members of the study teams in the different sites and deemed to fill a gap in awareness, knowledge or skills. Both studies received favourable approval from host organizations in HIC and local ethics' review boards.

Outline of the exemplar dementia studies with integrated capacity and capability development work

Study 1: SENSE-Cog Asia: This was a UK-funded single-arm, open-label, feasibility study of a culturally and linguistically adapted non-pharmacological intervention across seven sites in three South Asian countries (India, Pakistan and Bangladesh), in preparation for a definitive, fully powered randomized controlled trial (RCT). The study started in 2019 included participant dyads (PwD and their care partners) who received the intervention over an eight-week period. The intervention, involving the detection, assessment and management of concurrent hearing impairment and dementia in older community-dwelling adults, was delivered by a trained 'Hearing Support Practitioner' through six to eight individualized sessions over two months (dictated by need and participant-care partners desires). One site (Karachi) also delivered a vision intervention as well as the hearing intervention. The intervention comprised the following components: (i) Component 1: Clinical assessment and correction of hearing (vision) in an audiology and/or otolaryngology clinic (and eye clinic in Karachi); (ii) Component 2: Fostering adherence with hearing aids (and glasses in Karachi), focussed on the PwD; (iii) Component 3: Knowledge, awareness and communication skills about dementia and hearing (and vision in Karachi) impairment, focussed on the care partner; and (iv) Component 4: Recap/review of intervention components.

The primary aim of the study was to ascertain whether the study design and logistics, as well as the intervention itself, was feasible and acceptable to study participants, referral sources and the study team.

The protocol for SENSE-Cog Asia was based on a field study of the original intervention conducted in Europe¹² (ISRCTN number 35019114) that revealed high acceptability, feasibility^{13,14} and a positive signal for improving quality of life and addressing caregiver burden in a cost-effective way¹⁵. This intervention is being evaluated in a full-scale RCT in five European countries¹⁵ as part of the H2020-funded SENSE-Cog programme (www.sense-cog.eu H2020 Grant Agreement No. 668648).

Study 2: Rural Interventions for Dementia: This study was funded by the Indian Council of Medical Research (ICMR) to develop, adapt, test and implement interventions for dementia in a rural community in Thiriporur Taluk in Chengalpet District, Tamilnadu, South India. The study began in April 2019 and its objectives included: (i) identifying resources in the rural community; (ii) identifying needs of PwD and caregivers in the rural community; (iii) creating, adapting and manualizing interventions (that includes modified cognitive stimulation therapy); (iv) training community healthcare assistants to deliver interventions; (v) assess acceptability and feasibility of the interventions; (vi) establish effectiveness of delivering the interventions; and (vii) identify barriers and facilitators to implementing interventions in the rural community.

Results

The goals, actions and outcomes for capacity and capability building within the two exemplar studies are outlined in the Table.

People (human resources): Across the two studies, the number of newly trained research personnel included six local PIs, six study coordinators, seven research assistants, 11 intervention delivery personnel therapists and two raters. Four of the six local PIs (80%) had never taken the role of a research PI for a dementia trial before. The SENSE-Cog Asia study included a Trial Steering Committee (TSC), including four members who were new to the TSC role and agreed to continue contributing to the follow on larger RCT in the same capacity.

Research integrity and governance: Across the two studies, applications to five ethical review boards were required, which involved learning new procedures and instituting new policies at some of the study sites, particularly regarding the assessment of capacity to consent and the need to exclude participants without capacity due to lack of suitable legislative guidance

Table. Summary of the domains, actions, goals and outcomes of capacity and capability building in two exemplar studies of applied dementia research in South Asia

Domain	Goal	People (human resources)	Action to achieve the goal	Study 1: SENSE-Cog Asia	Study 2: RIDe	Actual outcome achieved
Local PIs	To have a clear understanding of the research process pathways involved in a Dementia study. To demonstrate an understanding of the roles and responsibilities of different individuals and organizations in clinical research.		Baseline and booster sessions of study specific training to be arranged (online, face to face, Skype or video link) along with the online GCP training to be documented in training log signed by the PI and verified by CI of the study.	7	1	1
Research assistants	To understand the process of accessing capacity, receiving informed consent; to demonstrate the ability to correctly and accurately complete CRF and other relevant documentation and understand the process for data query resolution. To ensure participant safety by correct reporting of adverse and serious adverse events.		Baseline and booster sessions of study specific training to be arranged (online, face-to-face, Skype or video link) along with the online GCP training to be documented in training log signed by the PI and verified by CI of the study.	7	1	1
Study coordinators	To identify the fundamentals of study set up to ensure an understanding of what should be in place before work on the study begins, including essential documents. To understand the role of audit, monitoring and inspection in clinical research.		Baseline and booster sessions of study specific training to be arranged (online, face-to-face, Skype or video link) along with the online GCP training to be documented in training log signed by the PI and verified by CI of the study.	5	1	1
Intervention practitioners (therapists)	To fully understand all the components of the intervention and how to deliver it.		Baseline and booster sessions of study specific training to be arranged (online, face-to-face, Skype or video link) along with the online GCP training to be documented in training log signed by the PI and verified by CI of the study. HSP capacity and capability checklist/HSP skills and knowledge checklist to be verified by senior sensory support therapist.	8	3	3

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Domain	Goal	People (human resources)	Action to achieve the goal	Study 1: SENSE-Cog Asia	Study 2: RIDe	Actual outcome achieved
PPI coordinators	To understand the principles of PPI (voice). To raise awareness of PPI design and methodology to enable local teams to decide on their approach. To establish a clear understanding of the role of the RUG. To be confident in managing and supporting the RUG, and in orientating RUG to their role within the project.	People (human resources)	Fortnightly or as required PPI training and awareness, baseline and sessions (online, face-to-face, Skype or video link) to be documented in training log and verified by central PPI coordinator.	7	N/A	N/A
Leadership	For PIs and study coordinators to understand the concept of leadership.		Training session and regular support to be provided from Chief Investigator and Trial manager.	10	1	
TSC	To monitor and supervise the progress of the study towards its interim and overall objectives. To review at regular intervals (quarterly) To consider new information relevant to the research question.		Invite three new members from each country become a TSC member under the supervision of the TSC independent chair based at HIC.	3	N/A	
Ethical review board	For each site (PIs and study coordinators) to understand the concept of ethics and able to obtain local and national ethic approval.		Training and supervision to be provided from project manager to understand the concept of Ethics Review Board and importance of having the approvals in place	10	6	
Research integrity and governance						
Ethical practice and value-based research principles						
GCP	All study personnel to receive GCP training prior to study start.		To deliver freely available on-line GCP training (https://gcp.nidatrain.org/) to be documented in the training log and to be verified by site PI and Chief Investigator.	100 per cent achieved		
Capacity to consent and consent procedures	All study personnel with participant contact to receive training to understand the process of accessing capacity and receiving informed consent.		Initial training to be delivered via Skype and video link before the start of study. Face-to-face workshops to be arranged to address any gaps and to provide extra support.	60 per cent trained with initial training package. One site needed five extra training sessions. Booster sessions and regular weekly supervision needed by the RAs and intervention personnel at all sites. 90 per cent were fully trained after the face-to-face workshops at 60 per cent of sites.		

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Domain	Goal	Action to achieve the goal	Actual outcome achieved
		Research integrity and governance	
		Ethical practice and value-based research principles	
Equipoise	All study personnel to have an appreciation of the concept of equipoise.	Training/discussions to be arranged to understand the distinction between a persuasive clinical approach, advocating for the positive outcome of an intervention, compared to a neutral, ‘observant’ approach with consideration of the risk of bias.	Hard to measure outcome More training and workshops needed after the initial discussion sessions. Workshops were arranged in September 2019 at Bengaluru and 2 sites in Pakistan. Ongoing remote training was provided to Dhaka site.
		Governance and quality control	
Trial documentation	Compliance with quality control checklists to GCP standards.	Extensive training to be provided by the study manager to all study coordinators and research assistance via SKYPE and video link.	78 per cent compliance with quality control checklists on first monitoring contact. Face-to-face workshop by the CI at five of the seven sites at site initiation visit Remote workshops by CI to remaining two sites.
Monitoring plan and visits	All sites to receive regular monitoring visits.	Study appointed monitor to visit all sites. Sites to be prepared for the visit with study documentation in good order.	70 per cent of sites received monitoring visits in person (the remainder was monitored remotely).
Budget management	Clarification on concepts around good budget management received sponsor and the study delivery sites, use of staff time sheets, scrutiny of budget statements, and funder audit. For India, approval and oversight of international research funds was also ensured through an application to the Health Ministry’s Screening Committee (HMSC).	Due diligence checks to be carried out by the host organization in HIC. Staff time sheets to be introduced, scrutiny of budget statements and funder audits to be undertaken. To apply for the clearance from Health Ministry’s Screening Committee in India.	80 per cent achieved before the start of the study in terms of contracts approval and due diligence checks. Clearance from HMSC in India caused a significant delay in the start of the study.
		Applied research delivery skills	
Quantitative outcome rating scales	To train all raters and therapists on rating scale administration and collection of quantitative data.	Initial training to be delivered via Skype and video link before the start of study. Face-to-face workshops to be arranged to address any gaps in the training.	100 per cent trained with booster sessions for all sites due to delay in study start. 46 per cent required additional training Additional training was delivered at 70 per cent of sites (Bengaluru, Chennai, Mysore, Karachi and Lahore). Remote video link booster sessions at remaining sites.
Qualitative interviewing and data collection	To train one researcher and one therapist per site in qualitative interviewing and data collection.	Qualitative training delivered via Skype and video link.	100 per cent trained with booster sessions for all sites.

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Domain	Goal	Action to achieve the goal	Actual outcome achieved
Data acquisition, entry and management	To train all study personnel with participant contact on data collection and data entry into electronic CRF.	Initial training delivered via Skype and video link before the start of study. Face-to-face workshops to address any gaps in the training.	70 per cent trained successful, based on monitoring visits. Booster sessions were arranged to achieve 100 per cent. Additional training was delivered at 70 per cent of sites (Bengaluru, Chennai, Mysore, Karachi and Lahore). Remote video link booster sessions at remaining sites.
Principles of collaborative working	To follow the principles of a 'rooted partnership' including co-production, as outlined in the 'Roadmap for Dementia Research' ²	Promote the 'ideal partnership' for research collaboration by incorporating the four pillars of: co-creation, capacity-building, sustainability and openness.	Hard to measure outcome; 80 per cent success in collaboration at all levels.
Development of an international funding proposal	To work in an interdisciplinary way and with an international consortium.	Provide a platform to work cross-nationally using video-links and cooperating to overcome national and local interests with the goal of securing funding for full-scale study with potential international impact.	Submitted a funding proposal for a full-scale international study to an international funder based on the feasibility study.
RUGs	To embed PPI ethos across 7 sites, by involving, engaging and informing patients and the public.	PPI and awareness raising, stigma, health literacy Patient and public activities	Mysore, India (i) world alzheimer day, (ii) community awareness walk, (iii) dementia awareness event for public members, (iv) dementia care skills event for professionals. Chennai, India. Dementia information sheets for the public created. Bengaluru, India. Recruitment materials and flyers co-developed. Lahore and Karachi, Pakistan. World Alzheimer Day Poster art competition on the issue of dementia in South Asia Lahore, Pakistan Radio programme on dementia awareness delivered Rawalpindi, Pakistan Topic guide for Alzheimer's day panel discussion for public Karachi, Pakistan Role play to raise public awareness of dementia Public newsletter about dementia produced and distributed locally Dhaka, Bangladesh Assessment of dementia checklist during hearing screening created and distributed

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Domain	Goal	Action to achieve the goal	Actual outcome achieved
Needs' assessment	To ascertain the level of KAP re-hearing, vision and cognitive impairment in an inter-professional group in Dhaka.	Administer a survey of KAP among interdisciplinary professionals.	56 responses were received identifying a high level of need for further training in dementia and sensory health KAS.
	To use the studies as a platform, to raise KAP regarding dementia in professionals from different disciplines.	Hold an interdisciplinary dementia study day in conjunction with study launch.	Interdisciplinary Dementia Study Day event held in Dhaka, Bangladesh (102 delegates from psychiatry, psychology, internal medicine, audiology, otolaryngology, nursing, speech and language therapy, human rights, social work and the volunteer sector).
Pathways to diagnosis, care and support			
Logistics	To identify logistic circuits to correct sensory impairment.	To provide supervision to the study coordinators to establish collaboration and logistic circuits for the provisions of hearings aids with audiologists and hearing aids companies.	100 per cent achieved.
Referrals/ recruitment	To establish new referral pathways and professional collaborations among audiology, otolaryngology, geriatric psychiatry, speech and language therapy, internal medicine outpatient and third sector agencies.	Provide supervision to the PIs and study co-ordinators to promote collaboration and establish pathways to referrals.	100 per cent achieved. New referral pathways and collaborations established (<i>i.e.</i> , among audiology, otolaryngology, geriatric psychiatry, speech and language therapy, internal medicine outpatient and third sector agencies. Links established among the general and private hospitals and non-governmental, non-profit mental health research organizations Memory clinic pathways established
KAS, knowledge, awareness and practice; RUGs, Research User Group; PPI, patient and public involvement; PIs, principal investigators; CRF, case report form; TSC, trial steering committee; GCP, good clinical practice; HSP, Hearing Support Practitioner; HIC, high-income countries; CI: chief investigator			

on the issue. Specific capacity assessment training was developed and delivered for the SENSE-Cog Asia study (Study 1) and a capacity assessment checklist was included as part of the record of the consent procedure.

Good Clinical Practice (GCP)¹⁶ training was a challenge due to a lack of locally relevant training packages, despite the requirement from the ethics boards for such training. To address this, each member of the research teams was required to undertake online, freely available GCP training, which was verified and signed off by the study chief investigators prior to site initiation. Twenty six members of the research team accessed the training for the first time.

The principle of clinical equipoise¹⁷ referring to the need to maintain a neutral stance in a clinical trial, or approaching a trial from the perspective of the null hypothesis, was a new concept to several research team members since, prior to working on these studies, the majority had only had clinical experience. Thus, training to understand the distinction between a persuasive clinical approach, advocating for the positive outcome of an intervention, compared to a neutral, ‘observant’ approach with consideration of the risk of bias, was necessary. This initially proved a challenge to some members of the team, particularly since they had been selected to be part of the research team based on their strong clinical skills and expertise.

Quality control, with GCP¹⁶ as the gold standard, was emphasized before and throughout the study, with specific training sessions regarding data collection, entry and management and trial documentation. Site initiation visits were conducted at all sites and addressed quality control issues early on. Monitoring visits for quality control and training purposes were conducted at all sites, with scrutiny of study documents, and, where possible, cross-referencing with source documents. For all seven SENSE-Cog Asia sites, monitoring was a new experience. Finally, budget management received attention using contracts between the sponsor and the study delivery sites, use of staff time sheets, scrutiny of budget statements and funder audit. For India, approval and oversight of international research funds was also ensured through an application to the Health Ministry Screening Committee.

Applied research delivery skills: The development of the domain of ‘dementia clinical research skills’ was particularly important and required a significant amount of knowledge, skills’ and attitudes’ training for the site teams to appropriately and ethically conduct

dementia clinical research with a potentially vulnerable population.

For the SENSE-Cog Asia study, this further training was delivered in several sessions prior to the chief investigator signing off each of the seven site initiation visits. Three of the sites had previous experience in non-dementia studies and required less training and support. In one site, engaging in clinical research was an entirely new experience, requiring additional training sessions, phone support from the central study coordinator and booster sessions. These were conducted using face-to-face sessions, as well as online methods (*i.e.*, SKYPE and video-link). The team in Pakistan (Karachi, Lahore and Rawalpindi), already very experienced in mental health research delivery, had participated in mandatory annual in-house research delivery training delivered in a five-day training workshop (Sharjah, United Arab Emirates), prior to study. However, this training was not specific to dementia research; thus, a dementia ‘day’ was included. In India, a bespoke training workshop for dementia research conduct and delivery was organized by an informal consortium of research-interested dementia clinicians and academics (the DEMReCON workshop) over a two-day period in Bengaluru, in September 2019. This included additional training on clinical research governance, ethical practice, data management and key aspects of trial delivery, using an interactive small group setting approach. Finally, detailed training in quantitative data collection using rating scales and qualitative data collection using focus groups was provided. The members of the RIDE intervention also participated in the DEMReCON workshop. In addition, the health-care assistants recruited from the rural community had no clinical exposure to dementia. They were provided training in basics of dementia identification and care.

International collaborations: Engaging in small, feasibility studies provided certain members of the research teams the opportunity to work in an interdisciplinary way and with an international consortium for the first time. Involvement in the multi-site study also enabled them to engage in follow-on work developing proposals for further funding from international funders. This involved working cross-nationally using video-links and cooperating to overcome national and local interests with the goal of securing funding for full-scale study with potential international impact. Following another principle of the ‘Research Roadmap for Dementia’²,

the concept of a ‘rooted partnership’¹⁸ for dementia research was introduced to the teams. According to this model, an ideal partnership for research collaboration should incorporate the four pillars of co-creation, capacity building, sustainability and openness¹⁸.

Patient and public involvement and awareness raising, stigma and health literacy: In SENSE-Cog Asia, we introduced PPI to the seven study sites and provided a PPI awareness and training programme to enable each of the sites to include a PPI component to their work. The teams were encouraged to co-design their PPI work with a local ‘Research User Group’ (RUG) comprised PwD and/or their care partners. The role of the RUG was to advise about key aspects of the delivery of the intervention, study conduct, recruitment and study materials (*i.e.*, patient information sheets). Each of the seven RUGs developed by the SENSE-Cog Asia team used a different ‘layer’ of the Wellcome Trust’s ‘Public Engagement Onion’¹⁹ with each layer the emphasis changes from two-way dialogue and co-design making (involvement) to conveying or information giving (engagement) as their approach.

For professionals, a notable example of awareness raising, reducing stigma and improving health literacy for dementia, took place in Dhaka in Spring 2019. Here, a study launch event for SENSE-Cog Asia was attended by 102 local professionals representing several different disciplines, including psychiatry, psychology, internal medicine, audiology, otolaryngology, nursing, speech and language therapy, social work, human rights and the volunteer sector. Furthermore, a survey of to ascertain the level of knowledge, awareness and practice of interdisciplinary professionals regarding sensory-cognitive health in older adults was administered in Dhaka (n=56) which revealed marked gaps across the range of disciplines and grades.

The RIDE study included PwD and their caregivers in the community along with the relevant stakeholders including service providers to co-produce and adapt interventions for dementia in rural India. The activities also included awareness raising events in the local communities in partnership with other agencies including non-government organizations (NGOs).

Pathways, logistics and referrals: For SENSE-Cog Asia, the interdisciplinary nature of the intervention, including cognitive and sensory health, meant that new referral pathways and professional collaborations were established, including among audiology, otolaryngology, geriatric psychiatry, speech and

language therapy, internal medicine outpatient and third sector agencies (*i.e.*, Alzheimer’s Pakistan in Lahore; Sir William Beveridge Foundation in Dhaka). Importantly, links were established among the general and private hospitals and non-governmental, non-profit mental health research organizations [*i.e.*, the Schizophrenia Research Foundation (SCARF) in Chennai, India; Pakistan Institute for Living and Learning in Karachi, Lahore and Rawalpindi]. In some cases, identifying potential participants for the study prompted the development of dedicated memory clinics embedded within other services such as internal medicine or speech and language therapy departments.

Pathway development was an important outcome for the RIDE study. Various stakeholders were identified, including healthcare staff in primary health centres (PHCs), community-based grass-root health workers such as *Anganwadi* staff, private general practitioners, local private hospitals and clinics run by NGOs and tertiary referral hospitals.

Discussion

We presented two examples of integrated research capacity and capability development from applied dementia research studies in South Asia. These demonstrate a ‘learn by doing’ approach²⁰. In our two studies, the most valuable aspect of our work was the development of a dedicated cadre of trained and capable research personnel to conduct and deliver the dementia research into the future as funding for definitive projects increases. A fundamental aspect of research capacity development is to equip researchers with the skills to disseminate and implement their findings into service development and meaningful health policy. Our initial steps have yet to extend to this level, but, as demonstrated by the number and variety of PPI initiatives conducted by our teams, the translation and dissemination element has already been started. However, the involvement of PPI in clinical dementia research is still emerging²¹ and the inclusion of PPI in LMIC work is limited²². PPI in research is described as ‘doing research with or by the public, rather than to, about, or for them’^{1,23}. It recognizes the centrality of patient and public’s viewpoints and concerns, and the recognition that their perspective may differ from those of researchers^{21,24}.

The United Nations Development Programme’s (UNDP)¹⁰ six guiding points for institutional-level capacity and capability development are (i) conducting training need assessment, (ii) engaging stakeholders on

capacity development, (iii) assessing capacity needs and assets, (iv) formulating a capacity development plan, (v) implementing a capacity development response, and (vi) evaluating the capacity development. Our approach, at the individual level, incorporated most of these six points. Since the teams were mostly new to dementia research, a formal training needs assessment was not undertaken as it was assumed that most, if not all, of the knowledge, attitudes and practice (KAP) needed for dementia research required training. However, in Dhaka, a formal 'KAP' survey of sensory-cognitive health was undertaken, with a view to wider training and dissemination beyond the specific SENSE-Cog Asia study (reported elsewhere). Using theory of constraint as a framework, a capacity development plan was formulated, with specific goals and actions to achieve those goals, and a means of evaluating the outcomes.

An aspect of point (v) 'implementing a capacity development response', is the need to iteratively monitor progress and establish systems of accountability and progress in KAP for dementia research. Our approach was to institute checklists for various aspects of the study and undertake site monitoring with real-time feedback. This was a new approach for several of the teams and it underscored the importance of quality control, GCP and ethical practice. There was a challenge in finding suitable GCP training. It was beyond the scope of our small studies to develop bespoke GCP training, necessitating open-source online training. There is an urgent need for appropriate GCP training packages to be developed and made freely available for emerging applied dementia research teams in LMIC settings.

According to the UNDP, 'knowledge is the foundation of capacity'¹⁰. However, in our case, focus was given on attitude and values-based research also. Specifically, the principle of clinical equipoise was important to our work; however, we found it challenging to imbue this principle through conventional means of training. A future action derived from our experience is to address this as an ongoing 'attitude' that can best be modelled or imparted through interactive group discussions in regular 'community calls' with concrete examples from the ongoing research studies. As members of the research teams develop experience and come to understand the impact of various forms of bias, attitudes such as equipoise may develop.

In conclusion, the statement, 'research is an integral part of global health' was issued nearly a decade ago²⁵

and was echoed by the WHO in 2012 through their statement, 'No Health Without Research'²⁶. The need for contextually relevant, evidence-based research is particularly strong for the development of diagnostic, care and support pathways for dementia. A research workforce trained for the dementia landscape is essential for the design, conduct and delivery of the research needed to raise awareness, reduce stigma, develop services and guide policy in South Asia²⁷.

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