MIDTERM PROGRESS REPORT

ILAE EPIACT Project

Bridging the Gender Gap in Epilepsy Care in Rural China

Chapter	China Association Against Epilepsy (CAAE)
EPIACT domains	Information and Access
Funding cycle	EPIACT Fund 2025–2027
Reporting point	Midterm narrative based on the approved project plan and field implementation to date
Project leader	Prof. Ding Ding

Executive Summary

This midterm report summarizes progress made under the EPIACT project "Bridging the Gender Gap in Epilepsy Care in Rural China". The project was originally designed around five linked workstreams: data collection, data analysis, partner mapping, community-based training, and public awareness. During the reporting period, the project moved from planning into implementation through a structured outreach activity in Wuzhi County, Henan Province, combining specialist service delivery, village follow-up, grassroots provider training, and real-world observation of gender-specific barriers to epilepsy care. In parallel, the project initiated preliminary analysis and delivered an early public awareness activity on International Women's Day (8 March 2026) focused on the social inequities faced by women with epilepsy, comorbidity management, and supportive care needs. Midterm progress is strongest in partner engagement, early-stage data collection, grassroots training, preliminary analysis, and the establishment of a practical implementation platform for the next phase.

1. Progress Against the Approved Work Plan

The table below aligns the approved project workstreams with progress observed by the midterm reporting point. It is intended to show how the original plan is being translated into implementation, while also indicating where early progress has advanced ahead of the original timeline and which activities now require consolidation in the next phase.

Workstream	Planned timeline	Mid-project milestone	Progress to date	Status / next step
Data Collection	Dec 2025–Dec 2026	Gender-specific survey design finalized and approved by stakeholders	**Initiated.** The field activity in Wuzhi County generated early observations on seizure control, medicine access, treatment interruption, stigma, and caregiving burden, and helped refine priority variables for later data collection.	**In progress.** Next step: finalize tools and expand structured patient-level data capture.
Data Analysis	Dec 2026–Jun 2027	Preliminary analysis report identifying priority gender gaps	**Initiated at a preliminary level.** Early review and preliminary analysis have begun, drawing on field observations and initial structured materials to identify priority domains including adherence, continuity of care, and gender-specific social constraints.	**In progress.** Next step: continue data cleaning and expand preliminary analysis once the first structured dataset is consolidated.
Partner Mapping	Dec 2025–Jun 2026	Initial partnership framework established with key stakeholders	**Substantially progressed.** Functional collaboration is already in place with the China Association Against Epilepsy patient support network; Wuzhi County Hospital of Traditional Chinese Medicine; Jiaozuo People's Hospital; Qibaijian Community Health Service Center of Jiefang District; Taihang Brain Hospital; and township- and village-level health facilities and providers in Wuzhi County.	**In progress.** Next step: further expand the partner network and deepen collaboration with key stakeholders to support follow-up, referral, and sustained implementation.
Community-Treatment Training	Mar 2026–Dec 2026	Core training program deployed in target communities	**Initiated.** During the Wuzhi field activity, local clinicians and community health workers received case-based exchange and brief training on standardized epilepsy care, gender-sensitive management, and long-term follow-up.	**In progress.** Next step: convert these sessions into a repeatable training package.
Public Awareness Campaign	Dec 2026–Dec 2027	First wave of awareness activities completed in priority areas	**Initiated ahead of the formal campaign timeline.** On 8 March 2026, the project delivered a large-scale public education and care-focused activity centered on women with epilepsy, highlighting social inequities, comorbidity management, and the need for practical care and support.	**In progress.** Next step: build on this early activity to design a broader awareness programme with local stakeholders and women's associations.

2. Project Rationale and Original Design

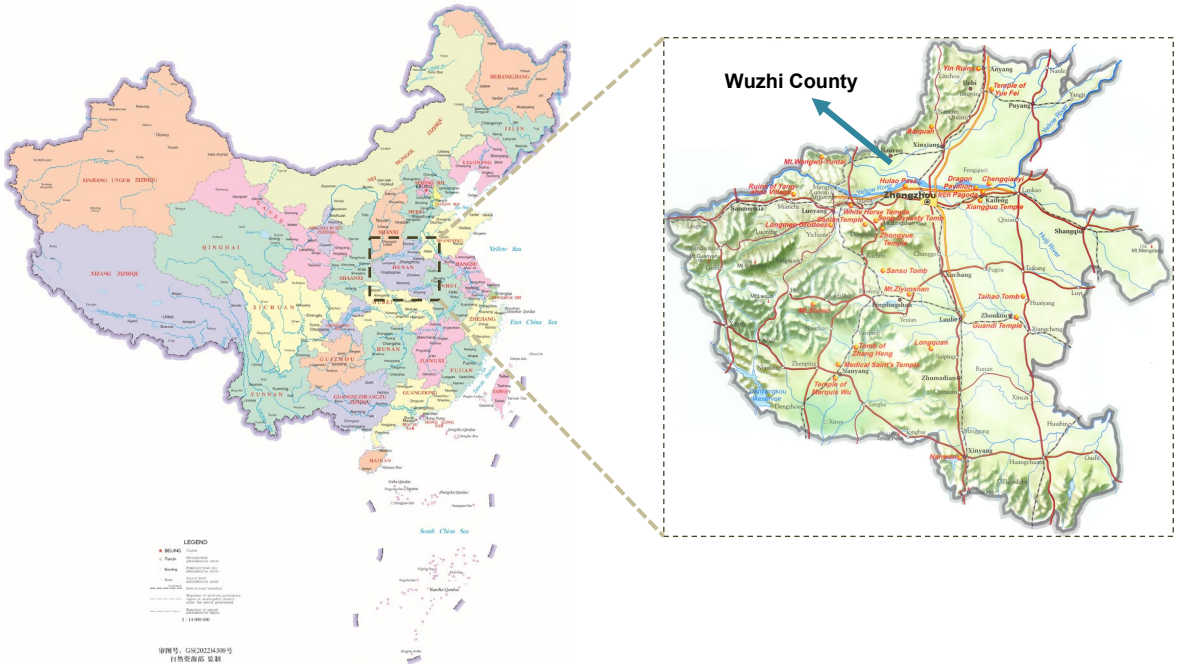
Bridging the Gender Gap in Epilepsy Care in Rural China was designed to address the persistent inequities experienced by women with epilepsy in under-resourced rural communities. The project is framed within the EPIACT domains of Information and Access and was conceived as a practical response to the combined effects of weak health infrastructure, limited access to antiseizure medicines, social stigma, and gendered household responsibilities. Rather than treating these as separate problems, the project was designed to connect evidence generation, service delivery, local capacity building, and community engagement within one implementation model.

The approved project plan organized the work into five linked activities: establishing standardized processes for gender-specific data collection; analysing the resulting data to identify priority gender gaps; mapping local partners across hospitals, community health workers, and women's associations; training local providers in epilepsy management and gender-sensitive care; and developing awareness activities to reduce stigma and improve treatment-seeking. This structure remains appropriate at midterm, and the reporting period has mainly focused on the foundational activities needed to make later analysis and wider-scale implementation feasible.

3. Reporting Period Activities

The most important activity during the reporting period was a structured field visit to Wuzhi County, Jiaozuo, Henan Province, from 8 to 13 March 2026. Wuzhi is a predominantly rural county in central China, located on the northern bank of the Yellow River in northwestern Henan. Although it has seen gradual development, many communities still rely on county-, township-, and village-level health services, and access to specialist care remains limited. The local economy is still closely tied to agriculture, and many women are mainly engaged in farming, household work, and family caregiving, often under modest economic conditions. This makes Wuzhi a highly relevant site for examining how everyday financial constraints, unequal caregiving burdens, and limited healthcare resources shape epilepsy care for women in rural China.

Under the guidance of the China Association Against Epilepsy (CAAE) patient support network, a multidisciplinary team led by Professor Ding Ding (vice president of CAAE) from Huashan Hospital, Fudan University, worked in collaboration with Jiaozuo People's Hospital, Wuzhi County Hospital of Traditional Chinese Medicine, Qibaijian Community Health Service Center of Jiefang District, Taihang Brain Hospital, and local township- and village-level health facilities. The activity combined specialist consultation, patient follow-up, grassroots provider exchange, and field-based inquiry into the lived realities of women with epilepsy in rural communities.



Location of Wuzhi County and its setting relevant to project implementation

During the hospital-based component of the visit, the team provided systematic assessment and follow-up for more than 100 patients. Services included seizure review, medication assessment, adherence counselling, electrocardiogram examination, and therapeutic drug monitoring. Particular attention was paid to the longer-term implications of antiseizure treatment for women and to important coexisting conditions such as skin comorbidities that might otherwise remain unmanaged.

Rural community settings and local primary-care environment in Wuzhi County

The fieldwork then extended beyond the county hospital into township facilities and households in Beiwang Village, Gao Village, Xiaodong Village, and Sanyang Township. The outreach was organized through coordination across multiple levels of the local health system, with participation from county-level hospitals, community health service centres, township facilities, and village-level providers. Patients were first identified through local follow-up lists and community contacts, and then seen through a combination of on-site consultation, household visits, and case review. During these visits, the team assessed seizure status, current medication use, treatment interruption, adherence problems, and follow-up needs, while also discussing practical care issues with family members and local providers. This field-based process allowed the project to move beyond routine outpatient contact and to observe barriers to care that are often not visible in clinic settings.

In parallel, the project initiated its public awareness work on 8 March 2026, coinciding with International Women's Day. A large-scale public education and women-focused care activity was organized with the participation of collaborating hospitals and local health providers. The event included free lectures, public education sessions, outpatient consultation and counselling services, and practical guidance for patients and families. Particular attention was given to the specific needs of women with epilepsy, including social inequality, treatment continuity, everyday self-management, and common comorbidities such as skin problems and other health conditions that may affect quality of life and long-term care. By combining public education with free consultation and women-focused guidance, the activity served both as a health outreach event and as the initial implementation of the project's awareness and advocacy component.

Project team and local partners during the field implementation

Public education and women-focused care activity

4. Midterm Achievements by Workstream

4.1 Partner mapping and local collaboration

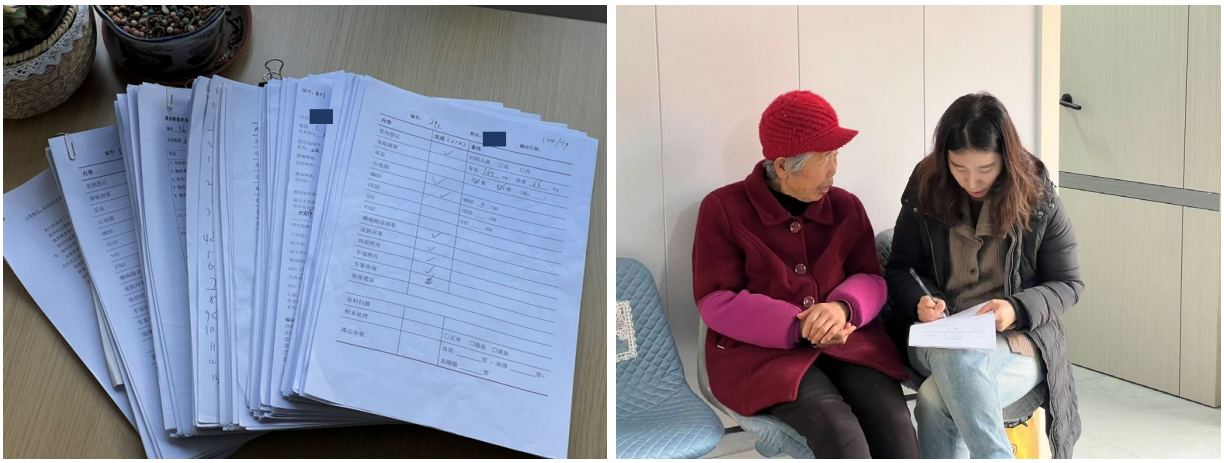
The partner-mapping workstream has progressed well and represents one of the strongest achievements at midterm. The reporting period demonstrated that functional collaboration is already possible across tertiary specialists, county-level institutions, community health service providers, township health facilities, and village-level contacts. In addition to the CAAE patient support network, active collaboration is already in place with Jiaozuo People's Hospital, Wuzhi County Hospital of Traditional Chinese Medicine, Qibaijian Community Health Service Center of Jiefang District, Taihang Brain Hospital, and multiple township and village-level health facilities in Wuzhi County. This is important because the project depends on durable local links rather than one-off outreach. The Wuzhi experience confirmed that trusted local partners are essential for case identification, logistics, follow-up, referral, and continuity of medicine access after the specialist team leaves.

Partner mapping and local collaboration meetings with hospitals, community health services, and

local providers

4.2 Early-stage data collection

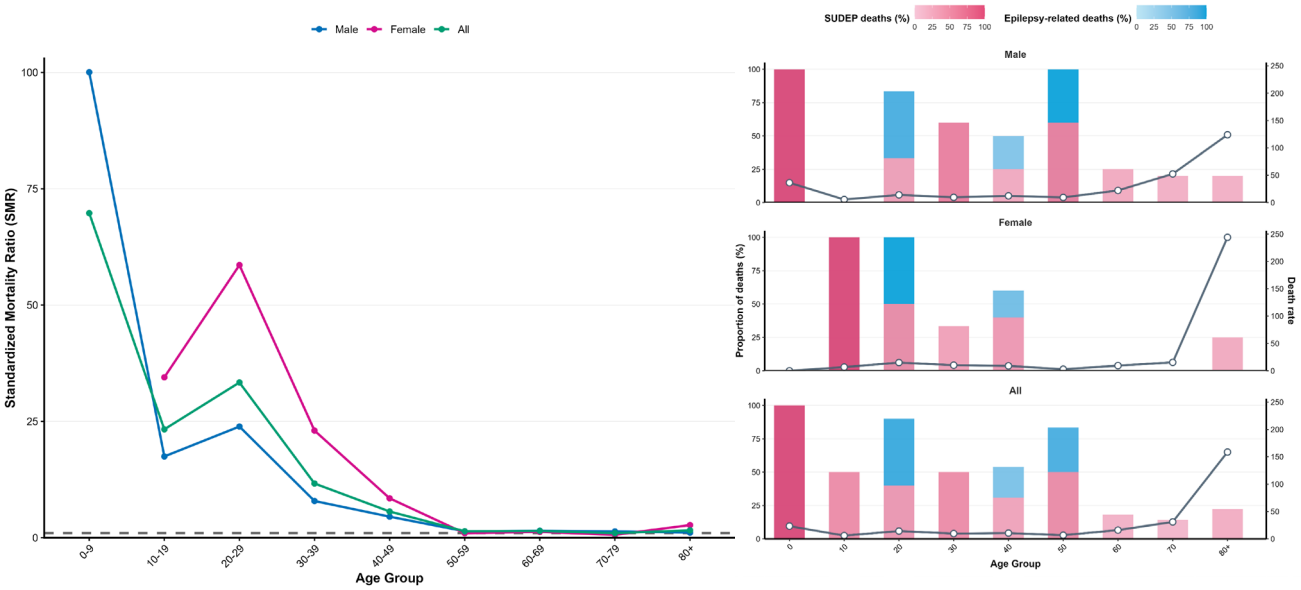
Although the project has not yet completed the full dataset envisaged in the original plan, meaningful progress has been made toward that objective. The Wuzhi field activity generated early observations on seizure control, medicine access, treatment interruption, stigma, and caregiving burden among rural women. Just as importantly, it helped refine which variables are likely to be most informative in the Chinese rural context, thereby supporting the next step of finalizing tools and expanding structured patient-level data capture.



Structured paper records for follow-up and patient-level data collection.

4.3 Preliminary data analysis

The data-analysis workstream has also begun at a preliminary level. While a larger standardized dataset is still needed for the full planned analysis, early review of cohort materials has already produced several relevant signals. In the ongoing 10-year community-based cohort of people with epilepsy in rural China, women showed a slightly higher age-adjusted standardized mortality ratio than men (2.52 vs. 2.26), as well as lower antiseizure medication use (78% vs. 83%) and lower effective seizure control (50% vs. 54%). Poor seizure control was also associated with both all-cause and epilepsy-related mortality, with a stronger effect observed in women. These preliminary findings support the project's focus on gender-related gaps in treatment access, seizure management, and long-term outcomes.



Preliminary gender-focused findings from the ongoing community-based cohort

4.4 Community-based training and provider support

The reporting period also advanced the training workstream. During the Wuzhi activity, clinicians from the county hospital, community health service centres, and township health facilities participated in case-based exchanges and brief on-site teaching focused on standardized epilepsy diagnosis, long-term management, and gender-sensitive care. The training covered updates in basic epilepsy knowledge and current guideline-informed practice, practical experience in antiseizure medication selection and use in resource-limited settings, and common issues in follow-up such as adherence, seizure monitoring, and treatment adjustment. It also emphasized the need to move beyond seizure control alone and to pay greater attention to comorbidity management and broader patient care needs. In particular, the sessions highlighted gender-related differences in care, including the need for greater awareness of the specific challenges faced by women with epilepsy, such as social disadvantage, under-recognition of symptoms, treatment interruption, and the management of common comorbidities and other special situations affecting female patients. These sessions were intentionally practical and embedded in real service delivery. This approach has begun to establish a train-and-support model that can later be formalized into a more structured and repeatable local training package.

Community-based training and provider support activities, including case discussion, on-site exchange, and practical guidance for local healthcare staff

4.5 Early public awareness and advocacy

The public-awareness workstream was also initiated earlier than originally planned. On 8 March 2026, marking International Women's Day, the project organized a large-scale public education and women-focused care activity. As part of this event, the project provided free lectures, public education sessions, and consultation services for patients and families, together with specialist-supported outpatient advice and practical guidance on epilepsy management. Particular attention was given to the needs of women with epilepsy, including counselling on gender-specific challenges, treatment continuity, everyday self-management, and supportive responses to social stigma and inequality. The activity also included education on comorbidity management, with specific attention to skin health and other common conditions that may affect quality of life, treatment experience, and long-term wellbeing. By combining public education, free clinical consultation, and women-focused counselling, the activity helped frame epilepsy care in a broader and more person-centred way, linking medical management with social support and practical daily care.

Early public awareness and advocacy activities, including Women's Day outreach, public education sessions, and engagement on women's epilepsy care and comorbidity management.

4.6 Identification of gender-specific barriers

A central purpose of the project is not simply to document a treatment gap, but to understand why women are disproportionately affected by it. The household visits made this especially clear. Women were often positioned within the family primarily as caregivers rather than patients, and their own health needs were repeatedly postponed or neglected. In some instances, treatment interruption reflected not a lack of medical advice alone, but the practical impossibility of prioritizing personal care while managing disability, poverty, or family dependence at home. These observations, together with the messages emerging from the International Women's Day activity, strongly support the project's original premise that gender inequity in epilepsy care is both clinical and social in nature.

Field-based interviews and follow-up activities

5. Emerging Findings and Lessons Learned

Several lessons have emerged by the midterm point. First, service delivery and evidence generation should not be treated as separate streams of work. In this project, direct clinical contact has been the main mechanism through which hidden barriers become visible and meaningful local data can be collected. Second, a gender-sensitive epilepsy programme in rural China requires more than technical improvement in prescribing practice. It must also engage with social stigma, household roles, low risk awareness, and fragile continuity of follow-up. Third, the value of local partnerships extends beyond access and logistics: local actors are essential to sustaining care, facilitating adherence, and ensuring that women identified during outreach do not become lost again once the specialist visit has ended. Fourth, early public engagement can play a useful role even before a full campaign is launched, particularly when awareness activities are linked to concrete concerns such as social inequity, comorbidity management, and supportive care for women with epilepsy.

6. Challenges and Risk Considerations

The project has encountered several practical implementation challenges that are highly relevant to rural epilepsy care. In many communities, access to diagnostic evaluation remains limited, and local facilities are often unable to provide more comprehensive investigations, which constrains both clinical decision-making and follow-up planning. Treatment options are also restricted in practice: the range of available antiseizure medications is limited at the primary-care level, and even when adjustment or optimization of treatment is clinically desirable, patients and families may not be able to act on these recommendations because of cost, travel burden, or unstable medicine supply. In addition, long-term management is often shaped by broader socioeconomic realities. Some women are unable to prioritize their own care because of household responsibilities, caregiving duties, or financial dependence, while stigma may further delay help-seeking and reduce adherence. These challenges do not weaken the rationale for the project; rather, they highlight the need for a pragmatic, context-sensitive approach that combines specialist input with realistic treatment planning, stronger community-level follow-up, and closer collaboration with local providers to improve continuity of care within existing resource constraints.

7. Priorities for the Next Phase

The next phase will focus on consolidating the early field experience into more structured and sustained implementation across all workstreams. For data collection, the immediate priority is to finalize the gender-sensitive survey tools and convert the lessons from the Wuzhi field activity into a clearer patient-level data collection framework, with more systematic capture of seizure control, antiseizure medication use, treatment interruption, access barriers, stigma, caregiving burden, comorbidities, and other gender-relevant factors. For data analysis, preliminary work has already started; the next step is to organize and clean the first structured dataset and continue descriptive analyses of gender-related differences in treatment, seizure outcomes, and mortality, so that priority gaps can be identified more clearly. For partner mapping, the project will further expand the partner network and deepen collaboration with county hospitals, community health service centres, specialist institutions, and village- and township-level providers, with the practical aim of improving referral pathways, medicine access, follow-up support, and continuity of care. For community-based training, the next step is to convert the case-based exchanges and brief on-site teaching already delivered into a more repeatable local training package, including updates in core epilepsy knowledge and guideline-informed practice, practical experience in antiseizure medication use in rural settings, greater awareness of comorbidity management, and more explicit attention to the specific needs of women with epilepsy. For public awareness and advocacy, the project will build on the International Women's Day activity by developing the next round of community outreach, including free lectures, consultation services, and women-focused counselling, with practical messages on stigma reduction, timely treatment-seeking, treatment adherence, skin health and other comorbidities, and the often-overlooked care needs of rural women with epilepsy. This progression remains consistent with the project's published EPIACT focus on Information and Access.

8. Conclusion

At midterm, the project has moved from planning into practical implementation and has made steady progress across its main workstreams. To date, it has established an initial operational model linking field service delivery, local collaboration, provider training, gender-sensitive data collection, preliminary analysis, and early public awareness activities. These early achievements provide a solid foundation for the next phase, particularly for expanding structured data collection, strengthening the partner network, and developing more sustained training and advocacy activities. Overall, the project remains feasible, relevant, and well aligned with its goal of improving more equitable epilepsy care for women in rural China.

Acknowledgements

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