A qualitative study of perceptions of professionals regarding multidisciplinary memory clinics for dementia care

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KEYWORDS
dementia, India, perception, qualitative study, multidisciplinary team, memory clinic

Received: 7 August 2022, **Revised:** 16 July 2024, **Accepted:** 30 July 2024

Popul. Med. 2024;6(August):22

https://doi.org/10.18332/popmed/191816

ABSTRACT

INTRODUCTION Dementia is a challenging problem across the world, with over 5 million people with dementia in India. Multidisciplinary memory clinics (MCs) are the mainstay of care for people with dementia in many countries. There is limited information about the understanding of and attitudes towards MC among health and social care professionals in India. This study aimed to identify the perceived advantages and disadvantages of a multidisciplinary memory clinic model in the care of people with dementia, and to identify the facilitators and barriers in establishing and running multidisciplinary memory clinics, as perceived by a group of specialist doctors, psychologists, and social workers.

METHODS A qualitative study using focus group discussions (FGDs) was conducted and the theoretical background of directed content analysis was applied for data analysis. The participants were from Kerala, a southern state in India, working in 13 different institutions involved in healthcare and social work. Purposive sampling was utilized for the FGD representative of a multidisciplinary team.

RESULTS All participants agreed that a multidisciplinary memory clinic approach would improve patient care. Early detection, comprehensive, continuous, person-centered care and caregiver focus were perceived benefits that MCs could offer. Disadvantages include unclear role definition, disjointed care, complex team dynamics, and high costs. Awareness of dementia, close involvement of stakeholders, clarity in role definitions, elder-friendly settings, community involvement and access to finances were perceived to facilitate establishing memory clinics while lack of awareness, stigma, risk of duplication of functions, lack of outcome assessment and lack of funding were barriers.

CONCLUSIONS Multidisciplinary memory clinics potentially facilitate early diagnosis of dementia and comprehensive person-centered care. Caregivers stand to benefit as the team has more time and diversity in skills to educate and support them.

INTRODUCTION

Dementia is fast emerging as a huge health and social care challenge impacting the national economy worldwide[1]. Every three seconds, there is a new patient with dementia somewhere in the world[2]. Developing countries are significantly affected and it is estimated that more than 5 million people with dementia live in India[3]. Central approach to dementia care is one of psychosocial interventions and support. As the condition deteriorates, the patient requires full-time care and assistance. The progressive nature and lack of cure make dementia a condition that causes major disability and burden[4]. This has a further negative impact on the income and financial status of the family. Families need information regarding this complex condition and have to develop skills to manage the psychosocial challenges, behavioral problems, environment and social systems around the patient[5].

Many developed nations have formulated national dementia strategies to tackle the challenge, and multidisciplinary memory clinics (MCs) are one of the mainstays of care in dementia, especially in the identification, investigation, and management of memory disorders[6,7]. A memory clinic/service is a multidisciplinary team that assesses and diagnoses dementia and provides psychosocial interventions for dementia[8]. These clinics facilitate early diagnosis and treatment[9] and support the person with

dementia and their family, from the onset of symptoms to the advanced stages. The first memory clinics were reportedly set up in North America during the mid 1970s, and in the UK shortly thereafter[10]. Changing view of Alzheimer's disease (AD) from senile dementia as an inevitable result of aging to a neurodegenerative disease contributed to the development of MCs[11]. MCs, in time, became a widely accepted healthcare service model for the care of people with dementia and other memory problems[7]. Memory clinics (MCs) have grown in popularity in many parts of the world. In the Netherlands, the number of MCs has increased eight-fold, the number of newly referred patients sixteen-fold, and the capacity per MC doubled from 1998 to 2011[12]. In the British Isles, the number of MCs grew from 20 in 1993 to 215 in 2019[13]. Raising awareness, better recognition, and realization of the relevance of a multidisciplinary approach in the timely diagnosis of dementia may all have contributed to the development of multidisciplinary care models in dementia.

Multidisciplinary approach which involves professionals from different backgrounds working together to provide comprehensive care for the patient and support the family, is intended to go beyond what traditional services can offer. Like many other low- and middle-income countries, India does not have a national dementia strategy, and the multidisciplinary mode of working in health and social care is in its infancy. Though there is no consensus about an ideal team composition, considering the nature of the needs of patients with dementia and their families, in addition to specialist doctors, the presence of social workers and psychologists are considered to be effective. These professionals would be able to address the medical and psychosocial needs of the patients and their caregivers[3,4,9]. Determinants of access to care[14] and factors influencing establishing services for dementia care[15] have been studied in Western settings. Barriers of accessing dementia care services include lack of information and knowledge, stigma, and services being too disease focused to the exclusion of psychosocial needs.

With the predicted number of people with dementia in the coming decades phenomenally high and a sparse number of specialists available to cater to their needs, the perceptions of professional stakeholders regarding a multidisciplinary care approach is essential and this study was undertaken to closely examine the facilitators and barriers in adopting a memory clinic model for dementia care in India. The aims of this study were to identify the perceived advantages and disadvantages of a multidisciplinary memory clinic model in the care of people with dementia, and to identify the facilitators and barriers in establishing and running multidisciplinary memory clinics, as perceived by a group of specialist doctors, psychologists, and social workers.

METHODS

Study design and participants

A qualitative study design using focus group discussions (FGDs) with different professional stakeholders was used to conduct this study. Institutional ethics committee approval was obtained for the study and informed consent from all the participants. The participants were from Kerala, a southern state in India working in 13 different institutions involved in health care and social work. Purposive sampling was utilized to select specialist doctors, psychologists, and social workers for the FGD representative of a multidisciplinary team. Nineteen participants were selected for three focus groups. Of the 19 participants, 7 were females and 12 males, 6 were social workers, 5 were psychologists, and 8 were psychiatrists.

Procedures and data collection

Format and questions for focus group discussions

The FGDs were conducted using Zoom video communication software and recorded. The conduct of FGDs was based on the manual specifically designed for this study and supported by a co-facilitator. The questions were: 1) 'Do you think the memory clinic approach improves patient care compared to a single doctor managing dementia care?', 2) 'What do you consider are the advantages/benefits of multidisciplinary memory clinics for the care of patients with dementia and their families?', 3) 'What do you perceive are the disadvantages/challenges of multidisciplinary memory clinics for the care of patients with dementia and their families?', 4) 'What factors do you think facilitate, establishing and effective functioning of multidisciplinary memory clinics?', and 5) 'What do you perceive are the challenges or barriers in establishing and running multidisciplinary memory clinics?'.

Data analyses

Content of the FGD was transcribed by the first author (JF), which another member of the team re-checked by comparing the transcribed text with the recording (CTSK). Data analysis was done manually. The theoretical background of directed content analysis was applied[16]. Qualitative data analysis was based on the method of Graneheim and Lundman[17] to ensure trustworthiness and conformity. Several of the main categories and sub-categories were identified from published literature and previous studies[3,4,13-15]. The analysis process consisted of the following steps: the text was divided into meaningful units, and they were further extracted and encoded. The initial codes were classified into sub-categories based on their similarities and differences. The sub-categories were sorted into categories. Themes linked meanings together in the categories. Subsequently, another research team member (PBJ) randomly selected sections of the transcripts and independently followed the same methodology to verify identified codes and resolve any thematic issues. This approach is helped to enhance the verifiability of the data analysis. The final codes were then categorized. Thematic saturation was reached after three focus group discussions. The process of peer checking was

used as a method of quality checking. Qualitative research review guidelines (RATS) and consolidated criteria principles for reporting qualitative research (COREQ) were followed[18].

RESULTS

Advantages and benefits of multidisciplinary MCs for dementia care

Nine themes emerged from the FGDs. Early detection was a major theme and evidenced by the quote:

'Multidisciplinary teams can help in early detection, through an initial screening by trained professionals. Otherwise, detection happens only when the family cannot manage the patient anymore.'

On the theme of 'more time to care' a participant commented:

'Time at outpatient department is not usually enough for dementia care and MC will have more time; Individual attention and more time is possible with MC, MC is better to help in diagnosis, based on longer time spent.'

Better care provision attributed to multidisciplinary team nature of the MC was identified as a theme about which a notable comment was:

'MC can support caregiving and facilitate better care in many ways as more members are involved in care due to the multidisciplinary nature.'

On the theme of more staff to care, teamwork was emphasized which would be beneficial for the patient as well as the family. Multidisciplinary team ensuring continuous care and the variety of skills individual members bring in, were recognized as major themes by the participants. The excerpt:

'MC can be useful to support patients and relatives in overall management with social, psychological and medical inputs.'

showcased the theme of comprehensive care. The participants identified that the multidisciplinary team can provide person-centered care as well as caregiver focus which also emerged as notable themes in the focus group discussions. Further excerpts are given in Table 1.

Disadvantages and challenges of multidisciplinary MCs for dementia care

The three themes emerged and relevant quotations are as follows and given in Table 2. Lack of clarity of role definition:

'Role confusion can occur when many professionals work together.'

'Overlap and lack of clarity in the roles of members of the MC can cause problems.'

On the theme of disjointed care within the team, a participant commented:

'Team miscommunication possibilities can affect care. Inconsistent instructions can be a problem for the team and patient. Members' work function overlapping is another

Table 1. Advantages and benefits of multidisciplinary memory clinics (MC) for dementia care, identified from focus group discussions by professionals, India 2022

Major themes	Sample excerpts
1. Early detection	*'MDT can help in early detection, through an initial screening by trained professionals. Otherwise, detection happens only when the family cannot manage the patient anymore.'*
2. More time to care	*'Time at outpatient department is not usually enough for dementia care and MC will have more time; Individual attention and more time is possible with MC.'* *'MC is better able to help in diagnosis, based on longer time spent.'*
3. Better care	*'MC can support caregiving and facilitate better care in many ways as more members are involved in care due to the multidisciplinary nature.'* *'Multiple assessments done as a package by different professionals help to understand the situation better and offer good solutions.'*
4. More staff to care	*'More professionals will definitely improve care.'* *'Teamwork can come together in MC to create an individual care plan for each patient, manage and better engage the patient and family.'*
5. Continuous care	*'If one of the team members is missing, others can take over, the patient always has support.'*
6. Varied skills	*'Professionals from different backgrounds come with different and useful skills.'*
7. Comprehensive care	*'MC can be useful to support patients and relatives in overall management with social, psychological and medical inputs.'* *'MC team is important, especially for the later phases when there are severe challenges.'*
8. Person-centered care	*'Team members would know the patient better.'* *'Individual care plan is needed for each patient, how to manage each state, how to engage the patient, thus the team can come together and plan that.'*
9. Caregiver focus	*'More information and awareness can be provided; Family can be educated; Family can be supported.'* *'Upskilling family members in identifying the stages and symptoms and how to handle the disease course.'*

Table 2. Disadvantages and challenges of multidisciplinary memory clinics (MC) for dementia care, identified from focus group discussions by professionals, India 2022

Major themes	Sample excerpts
1. Lack of clarity of role definition	*'Role confusion can occur when many professionals work together.'* *'Overlap and lack of clarity in the roles of members of the MC can cause problems.'*
2. Disjointed care within the team	*'Team miscommunication possibilities can affect care.'* *'Inconsistent instructions can be a problem for the team and patient.'* *'Members' work function overlapping is another problem; it is seen in hospitals how the patient goes through the same repeated questions and assessment and it is distressing for patients.'*
3. Complex team dynamics	*'When staff from different backgrounds come together as a team, power struggle and clash of opinions can happen.'*

Table 3. Facilitating factors for establishing the effective functioning of multidisciplinary memory clinics (MC) for dementia care, identified from focus group discussions by professionals, India 2022

Major themes	Sample excerpts
1. Awareness among stakeholders	'If there is good awareness regarding dementia and its care among all those involved, MC will be a success.' 'We have to increase awareness among the public about dementia, maybe use radio /TV, etc., simplify symptoms, in short, create the need.' 'Increase awareness of dementia. Similar to eye camps for cataract, may be there should be memory camps.'
2. Close involvement of stakeholders	'Stakeholders should come together, including local and community representatives, primary health centers, etc.'
3. Role definitions	'There should be a proper structure for the team with clear cut roles, responsibilities, strategy, goals to facilitate clinic work irrespective of who comes or goes in the team, - SOP needed for a professional approach.'
4. Elder-friendly settings and approach	'The MC should have a homely atmosphere and not like a hospital; welcoming senior citizens.' 'The services should be elderly-friendly.'
5. Availability of skilled and motivated staff	'If there are professionals who have the required skills and are motivated to work, that would be great.' 'All staff, even existing ones, should get adequate training.' 'Rather than extra new people, we can think of restructuring existing team members'.
6. Good networking and community involvement	'The team should have good relationships with the local community.' 'Networking with community is needed for success; networking with other hospitals, departments too.'
7. Access to finances	'Social and financial support by local funders should be arranged.' 'A public-private partnership would be ideal to ensure financial support.'

SOP: standard operating procedure.

problem.'

Complex team dynamics was another theme identified as exemplified by the comment:

'When staff from different backgrounds come together as a team, power struggle and clash of opinions can happen.'

Factors that help to establish, facilitate, and assist in the effective running of multidisciplinary MCs

Awareness among stakeholders was a major theme identified:

'If there is good awareness regarding dementia and its care among all those involved, MC will be a success. We have to increase awareness among the public about dementia, maybe use radio/TV, etc., simplify symptoms, in short, create the need. Increase awareness of dementia. Similar to eye camps for cataract, may be there should be memory camps..

Close involvement of the stakeholders emerged as a notable theme as the participants emphasized the need for multiple agencies to come together to facilitate the effective running of multidisciplinary memory clinics:

'Stakeholders should come together, including local and community representatives, primary health centers, etc.'

Role definitions of team members were identified to be important to facilitate the smooth running of the MC, with a

Table 4. Challenges or barriers in establishing and running multidisciplinary memory clinics (MC) identified from focus group discussions by professionals, India 2022

Major themes	Sample excerpts
1. Lack of awareness	*'Lack of awareness regarding dementia is a major barrier. Many people do not understand what it is and see it as a normal part of ageing. They do not get the help they need.'* *'Even some health and social care professionals do not have good understanding of the condition.'*
2. Stigma	*'Ageism is an issue, "why do more for these old people?" is a general attitude seen.'* *'Acceptance of the public is a major issue. They can be sceptical.'* *'There can even be a stigma attached to the clinic.'*
3. Risk of duplication of functions	*'Lack of proper communication even if others may have collected data; sharing and proper communication is important.'*
4. Lack of outcome assessment	*'If the community does not see the results, it will be a failure.'* *'There should be at least yearly evaluation.'*
5. Lack of funding	*'A lot of expenses needed to set up MC.'* *'Cost issues and arranging the resources are major problems.'*

participant commenting:

'There should be a proper structure for the team with clear cut roles, responsibilities, strategy, goals to facilitate clinic work ...'

Elder friendly settings and approach were an important facilitating factor for effective functioning of multidisciplinary memory clinics. Availability of skilled and motivated staff as a theme was evidenced by the participant's quote:

'If there are professionals who have the required skills and are motivated to work, that would be great.'

The importance of good networking and community involvement was a theme exemplified by multiple comments by participants including:

'The team should have good relationships with the local community.'

The final theme was the importance of access to finances including the suggestion:

'A public-private partnership would be ideal to ensure financial support.'

Further information on the themes is available in Table 3.

Challenges and barriers in establishing and running multidisciplinary MCs

One of the most relevant themes recognized was lack of awareness. As one of the participants commented:

'Lack of awareness regarding dementia is a major barrier. Many people do not understand what it is and see it as a normal part of ageing. They do not get the help they need.'

Stigma emerged as a major challenge, with a participant making the remark:

'Ageism is an issue, "why do more for these old people?" is a general attitude seen.'

Risk of duplication of functions is a challenge to overcome as noted in the following quote by a participant:

'Lack of proper communication even if others may have collected data; sharing and proper communication is important.'

Lack of outcome assessment is a barrier to overcome in running a multidisciplinary MC as commented by a participant:

'If the community does not see the results, it will be a failure.'

The final theme identified as a challenge was, the lack of funding. Further details on all these themes are given in Table 4.

DISCUSSION

This study looked at the perceptions of professional stakeholders regarding multidisciplinary memory clinics from a developing country setting. With an increased interest in interdisciplinary approaches of care[3] this information is important for those who are considering to establish such models of care. A memory clinic typically consists of a specialist doctor (psychiatrist, neurologist, geriatrician) with other professionals such as psychologists, social workers, nurses, occupational therapists, etc. The variety and number of professionals in the team depend on the local policies and resources. In resource scarce developing country settings, even small informal teams can provide efficient memory clinic services as detailed in the guidelines brought out by Alzheimer's and Related Disorders Society of India[19].

The benefits of the multidisciplinary dementia care approach reported in this study include early detection, more time to care, better care, more staff to care, continuous care, varied set of skills on offer for care, comprehensive care, person-centered care, and caregiver focus.

Several of these themes are also shared by other studies

from different parts of the world[7, 20]. Early diagnosis provides timely access to a pathway of evidence-based treatment. By virtue of having more time and resources for assessments and the support of a multidisciplinary team, MCs can potentially facilitate an early diagnosis. This allows people with dementia to receive timely treatment and families to plan, and get practical information, advice, and support[21]. With their inherent skill mix, multidisciplinary teams are more suitable for managing cognitive impairment and behavioral and psychological symptoms associated with dementia (BPSD) than traditional care models. Knowledge and skills acquired with education and training, effectively reduce BPSD[22,23]. Multidisciplinary team approaches and individualized treatment plans developed according to the unique needs of the individual with dementia, combined with caregiver problem-solving techniques, are key features of successful education and training interventions[24,25]. The key elements of person-centered care include knowing the person as an individual and providing meaningful care to the person[26]. Empirical studies demonstrate that the application of person-centered care results in reduced neuroleptic medication use and agitation[27]. Multidisciplinary approach relies on shared responsibility. It allows team members to focus on the issues most relevant to their own area of expertise[28]. Caregivers stand to benefit as the team has more time and diversity in skills to educate and support them.

Lack of clarity of role definition, disjointed care, and complex team dynamics were concerns expressed by the participants as potential disadvantages of this model of care. There needs to be clarity in the responsibilities of each member of the team and appropriate guidelines[19] may be followed to avoid duplication of work and disruption in care. Any ambiguity in the specific role of each member, unfamiliar to multidisciplinary team working, can be thus resolved avoiding the risk of potential disjointed care. There may be differing opinions in the management plan which can lead to difficult team dynamics and may impact patient care. However, the participants noted that when a dedicated team of professionals from different backgrounds work in an organized manner with a strong leadership, these challenges could effectively be addressed.

Memory clinic care pathway is multidisciplinary in its essence. The referrals may be from doctors and other professionals[3,19]. The primary responsibility of the specialist doctor in the MC is to investigate and diagnose or rule out dementia using validated criteria and practice guidelines. When diagnostic uncertainty exists, referral to an appropriate specialist may be helpful for diagnosis clarity. Following diagnosis, a treatment plan can be formulated to address the disease and underlying symptoms[28]. This person-centered care plan is formulated by the multidisciplinary team after their assessments, by identifying the individual psychological, social and nursing care needs of the patient which differ from person to person. This care plan needs to be periodically reviewed to adapt to the progressive changes in symptoms, functions and personal circumstances. Caregiver needs are also addressed by the MC by providing information, training and supporting them through the dementia care journey as the process of caregiving is often stressful and there should be special emphasis on supporting their physical and mental health as well[3]. Social workers have a significant role in healthcare and in many resource-rich countries, social services sector under the government is well developed. The role of social workers is being increasingly recognized in India, and they become more effective when they have close contact with the community they work with and have good knowledge of local resources. Nurses are skilled in monitoring symptom presentation, responding to medication issues, educating and providing relevant information to family members and assisting them in preparing for disease progression. Many questions families ask related to activities of daily living can be satisfactorily addressed by them. They are well placed to take a coordinating role with appointments and record keeping. The social worker or psychologist can take the lead in assessing and advising the families on the management of BPSD once medical problems are ruled out. Behavioral analysis of the patient and psychological assessment of the caregivers can also be conducted by clinical psychologists. Physical therapists/physiotherapists can assist patients with dementia to optimize their physical conditioning and maintain safe mobility, helping to prolong independent living and reduce the need for institutionalization[29] or hospitalization. Occupational therapists help the patient and their caregivers to adapt to the patient's diminished ability to deal with challenges faced in daily living. The use of devices to assist with toileting, eating, dressing, and home management can be recommended and demonstrated by an occupational therapist. As patient independence is enhanced, caregiver burden decreases[30]. Dietary intake is an essential quality of life determinant[31] which would require input from a dietician. Speech and language therapists when available can utilize their skills in managing difficulties associated with communication, swallowing, and related problems.

Awareness regarding the impact of dementia among the stakeholders and their close involvement in service development, clear role definitions, elder-friendly settings and approaches, availability of skilled and motivated staff, good networking, community involvement, access to finances were identified as facilitating factors by the participants in establishing and functioning of an MC, while lack of awareness, stigma, risk of duplication of work, lack of outcome assessment and lack of funds were some of the barriers noted. Age-friendly settings as recommended by the World Health Organisation[32] are a factor identified by the participants as a facilitator and concept of dementia friendly communities has to be seen parallel to this development[33]. Raising awareness regarding the social and economic impact of dementia among all sections of society including government bodies and funding agencies is critical. Close

involvement of different stakeholders including, but not limited to, health and social care professionals, patients with dementia and their caregivers, and governmental and voluntary organizations, facilitate establishing and effective functioning of memory clinics. As the care is continuous and extends to the community, good networking and community involvement are essential. Standard operating procedure (SOP) and clear role definitions help run memory clinics smoothly[19]. There should be clear leadership and established pathways of care. Defining the model used and specifying the interventions applied help in assessing the outcomes. The use of validated instruments such as those to monitor cognitive functions, activities of daily living, quality of life and caregiver stress to quantify outcome measures, help in demonstrating the effectiveness and quality of interventions at the memory clinic.

High service costs have been a concern expressed by our participants. Due to the competing nature of healthcare needs, innovative means of fund raising looking at local resources and assets involving local community may be explored. Asset-based community development (ABCD) is a methodology for the sustainable development of communities based on their strengths and potential. Related to tenets of empowerment, it postulates that solutions to community problems already exist within a community's assets[34,35]. While a team consisting of a large number of multidisciplinary team members is viable in resource rich settings, including teaching institutions, other centers may need to explore innovative ways of skills utilization and management. This may include a regular team which may be small (e.g. doctor, nurse, and a social worker) with visiting services of professionals employed in other departments or services (e.g. neurologist, psychologist, physiotherapist etc.) on a sessional basis. Such arrangements would need the support of the officiating authorities.

The participants in this study concur that there is a definite advantage for the multidisciplinary memory clinic approach over conventional outpatient-based dementia care. Professional groups usually represented in multidisciplinary memory clinics identified the perceived benefits and possible disadvantages of memory clinics along with the facilitators and barriers in establishing and running them.

Limitations

This study has certain limitations. There was no representation from other multidisciplinary groups such as neurologists, nurses, physiotherapists, occupational therapists and dieticians. As this study was intended to identify the perceptions of professional stakeholders, no participation of patients and their caregivers was planned. The study also has inherent limitations of qualitive studies such as a small sample size making the findings difficult to generalize, the potential influence of the researchers' background on data interpretation, and the uniqueness of the approach making it difficult to replicate the findings.

CONCLUSIONS

Multidisciplinary memory clinics can potentially play a role in facilitating early diagnosis of dementia and comprehensive person-centered care. With their inherent skill mix, multidisciplinary teams are possibly more suitable for managing cognitive impairment and behavioral and psychological symptoms associated with dementia than traditional care models. Caregivers stand to benefit, as the team has more time and diversity in skills to educate

and support them. Improved awareness about dementia among all stakeholders is a prerequisite for establishing functioning memory clinics. Standard operating procedures and clear role definitions help to run memory clinics smoothly. Raising awareness regarding the social and economic impact of dementia among all sections of society is critical. Close involvement of different stakeholders including, but not limited to, health and social care professionals, patients with dementia and their caregivers, and governmental and voluntary organizations, facilitates establishing effective functioning memory clinics.

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CONFLICTS OF INTEREST
The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none was reported.

FUNDING
There was no source of funding for this research.

ETHICAL APPROVAL AND INFORMED CONSENT
Ethical approval was obtained from the Institutional Ethics Committee of Rajagiri Institutional Ethics Committee (Approval number: RAJH/2020/002; Date: 15 February 2020). Participants provided informed consent.

DATA AVAILABILITY
The data supporting this research are available from the authors on reasonable request.

PROVENANCE AND PEER REVIEW
Not commissioned; externally peer reviewed.