Engaging African American Veterans with Health Care Access Challenges in a Community Partnered Care Coordination Initiative: A Qualitative Needs Assessment

Adriana Izquierdo, MD, MSCE[1,2,3]; Michael Ong, MD, PhD[1,2,3]; Felica Jones,[4]; Loretta Jones, MA, ThD, PhD[4,5]; David Ganz, MD, PhD[2,3,6,7,8]; Lisa Rubenstein, MD, MPH[1,2,3,8]

Background: Little has been written about engaging potentially eligible members of a health care system who are not accessing the care to which they are entitled. Knowing more about the experiences of African American Veterans who regularly experience health care access challenges may be an important step toward equitable, coordinated Veterans Health Administration (VHA) care. This article explores the experiences of African American Veterans who are at risk of experiencing poor care coordination.

Design: We partnered with a community organization to recruit and engage Veterans in three exploratory engagement workshops between October 2015 and February 2016.

Participants and Setting: Veterans living in South Los Angeles, California

Main Outcome Measures: Veterans were asked to describe their experiences with community care and the VHA, a division of the US Department of Veterans Affairs (VA). Field notes taken during the workshops were analyzed by community and academic partners using grounded theory methodology to identify emergent themes.

Results: 12 Veterans and 3 family members of Veterans participated in one or more engagement workshops. Their trust in the VA was generally low. Positive themes included: Veterans have knowledge to share and want to help other Veterans; and connecting to VA services can result in positive experiences. Negative themes included: functional barriers to accessing VA health care services; insensitive VA health care environment; lack of trust in the VA health care system; and Veteran status as disadvantageous for accessing non-VA community services.

Conclusions: Veterans living in underserved areas who have had difficulty accessing VA care have unique perspectives on VA services. Partnering with trusted local community organizations to engage Veterans in their home communities is a promising strategy to inform efforts to improve care access and coordination for vulnerable Veterans. *Ethn Dis*. 2018;28(Suppl 2):475-484; doi:10.18865/ed.28.S2.475.

Keywords: Veteran Engagement; African American; Care Coordination; Quality Improvement; Community-Partnered

[1] Department of Medicine, University of California, Los Angeles, CA
[2] VA Greater Los Angeles Healthcare System, Los Angeles, CA
[3] Center for the Study of Healthcare Innovation, Implementation and Policy, VA Greater Los Angeles Healthcare System, North Hills, CA
[4] Healthy African American Families II, Los Angeles, CA
[5] Charles R. Drew University of Medicine & Science, Los Angeles, CA
[6] Geriatric Research, Education and Clinical Center, VA Greater Los Angeles Healthcare System, Los Angeles, CA
[7] Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, CA
[8] RAND Corporation, Santa Monica, CA

Address correspondence to Adriana Izquierdo, MD, MSCE; Department of Medicine, University of California, Los Angeles and VA Greater Los Angeles Healthcare System. 11301 Wilshire Blvd, Building 500, Room 4001, Los Angeles, CA 90073. adriana.izquierdo@va.gov.

Introduction

Patient engagement is of increasing importance and relevance to health systems responsible for population health,[1-12] including the Veterans Health Administration (VHA) of the US Department of Veterans Affairs (VA). Veteran engagement was recently added as a core organizational principle among VHA's strategic goals.[13] VA's Health Services Research and Development Service (HSR&D) – through national initiatives such as the Veteran Engagement Initiative and the Quality Enhancement Research Initiative (QUERI) – has made major efforts to enhance patient engagement and partnered research.[12]

Engaging Veterans who feel marginalized from the VA in partnered research presents a novel challenge, as little established evidence or expert guidance exists on how to identify, reach out to, gain the trust of, and build and sustain working collaborative research partnerships with marginalized patients in general and Veterans specifically, particularly those Veterans who have had negative experiences with VA

health care access and services. Veteran mistrust of the VA may present a significant obstacle to building effective collaborative research partnerships between academic investigators and marginalized Veterans. Moreover, it is unclear how engaging marginalized Veterans in partnered research could inform and impact the development of an intervention to improve care.

We invited Veterans to become active and equal partners in a quality improvement project to develop, implement and evaluate a community-enhanced care coordination intervention for Veterans being discharged home from the hospital.

In this article, we describe the initial process we employed as part of the VA Care Coordination QUERI to engage a group of marginalized African American Veterans from a socioeconomically disadvantaged region in Los Angeles in partnered research. Specifically, we invited Veterans to become active and equal partners in a quality improvement project to develop, implement and evaluate a community-enhanced care coordination intervention for Veterans being discharged home from the hospital. We also report the qualitative findings on Veterans' experiences with VA care that emerged from the initial meetings of our partnered work.

Methods

Design

VA health services researchers (AI, MO, LR) first partnered with Healthy African American Families II (HAAFII), a non-profit community-based organization located in South Los Angeles and leader in community advocacy and community-partnered participatory methods.[14] HAAFII has more than 20 years' experience engaging diverse stakeholders (eg, families, caregivers, health care providers, health services researchers, lay persons, churches, businesses, community organizations, county and city officials) in partnered work to advance research, policy, advocacy, and services implementation initiatives to improve health outcomes in Los Angeles County, especially among ethnic minority and socioeconomically disadvantaged populations.[15-17] For our project, in addition to providing expertise on the design and operationalization of partnered work, HAAFII facilitated working directly and collaboratively with the targeted Veterans who reported feeling or being disengaged, marginalized, alienated, isolated, and/or disenfranchised from the VA health care system.

HAAFII coordinated meetings to include Veterans and academic investigators (AI, MO, LR). HAAFII explicitly stated that the purpose of these meetings was to initiate the process of Veteran engagement in a partnered initiative that employed a CPPR approach to improve care coordination for Veterans being discharged home from the hospital. To align more precisely the terminology with CPPR principles of shared decision making and joint collaboration,[18] HAAFII advised referring to the Veteran meetings as, "Veteran engagement workshops," as opposed specifically to Veteran "focus groups" or "discussion groups."

HAAFII facilitated the Veteran engagement workshops and began each workshop with introductions and an icebreaker. HAAFII then reviewed the principles and process of CPPR (eg, equal partnership, joint collaboration, two-way knowledge transfer), what individual community and academic partners' responsibilities were (eg, open communication, trust, respect), and what Veterans could expect from participating in a community partnered project (eg, short-term deliverables, longer-term outcomes, capacity building, network building). HAAFII and the academic investigators co- presented the objectives (ie, to develop a community-enhanced care coordination intervention for Veterans being discharged from the hospital) and methods (ie, a CPPR approach) of the project. HAAFII identified the engagement workshops as the set-

ting in which the partnered work would begin. To focus the development of intervention on the issues and needs of Veterans, the engagement workshops included an exploratory evaluation of Veterans' experiences with VA health care access and services. This exploratory work was reviewed by the VHA Office of Patient Care Services and was determined to be non-research.

Setting and Recruitment

The Veteran engagement workshops were held at HAAFII. HAAFII is in the South Los Angeles region, which has a population of more than 1 million individuals[19] and has high rates of unemployment, homelessness, avoidable hospitalizations, and lack of health insurance.[20-22] There are no VA Greater Los Angeles Health Care System (VAGLAHCS) facilities are in the South Los Angeles region. Using HAAFII as the geographic point of reference, the closest VA primary care facilities are in downtown Los Angeles or West Los Angeles (also the closest VA medical center [VAMC]), 9 and 17 miles away, respectively).

Recruitment was conducted by HAAFII who had, through advocacy work and community engagement activities previously conducted, established relationships with African American Veterans living in South Los Angeles. HAAFII recruited Veterans directly to participate in a series of engagement workshops to learn about CPPR and to become part of a community partnered VA quality improvement project to improve care coordination for hospitalized Veterans being discharged home. HAAFII asked the Veterans they knew and had worked with to invite fellow Veteran colleagues and friends.

Data Collection

Three Veteran engagement workshops were held over six months (October 14, 2015; December 2, 2015; February 10, 2016). After giving an orientation to CPPR and the VA QUERI project as described above, HAAFII asked Veteran participants three open-ended questions: 1) "What have been your experiences with the VA health care system and services?" 2) "What have been some of the problems you have faced with the VA health care system and services?" and 3) "What have been some of the strengths you have encountered with the VA health care system and services?" Although Veterans were not asked explicitly to suggest ways to improve the VA health care system and its services, Veterans spontaneously shared recommendations for change. Each engagement workshop lasted approximately two hours. Field notes were taken during each engagement workshop by one of the academic investigators (AI). Notes were reviewed for accuracy and completeness by community (FJ, LJ) and academic partners (LR, MO), who were present at all three engagement workshops.

Analyses

Data in the form of field notes were analyzed using grounded theory methodology, which employs thematic content and constant comparative methods to identify the range and salience of themes characterizing the phenomenon being studied.[23] Field notes were analyzed by an investigator (AI) with qualitative research expertise, who grouped field note segments with similar content into codes or subthemes. The investigator then searched across codes for concepts that were shared or that linked codes together as themes. Field note segments for codes and themes were reviewed with two community partners (FJ, LJ) and two academic investigators (MO, LR) to revise and refine defining features of each theme. Discordant views regarding the interpretation and sorting of concepts were resolved via consensus. For example, one of the academic investigators (AI) initially proposed linking together a series of codes describing Veterans' experiences with a lack of timely change on behalf of the VA in response to Veterans' stated needs, and with feeling disrespected by the VA, under the concept, or theme, "Lack of VA health care system responsiveness." In a roundtable discussion held among the academic investigators and community partners to analyze the data, the community partners suggested linking the codes describing these experiences under the concept, or theme, "Lack of trust in the VA health care system." They contended that lack of trust was a recurring concept and a major theme, and that Veterans' experiences with a lack of timely change and with feeling disrespected highlighted key mechanistic features whereby Veterans lost trust in the VA system. As a group, we

Table 1. Qualitative themes, sub-themes (Veterans' experiences), and suggested improvements

Main themes	Sub-themes – Veterans' experiences	Suggested improvement
Functional barriers to VA health care services access	Lack of VA health care services in South Los Angeles	Build a clinic in South Los Angeles
	Transportation challenges	Make ACCESS transportation requirements more permissive; simplify ACCESS transportation application process
	Difficulties initiating access to VA health care services	Develop a user-friendly VA-community website; start a community support group, "For Vets by Vets"; develop Veteran-directed outreach by implementing a community "drop-in" center
	Difficulties maintaining access to VA health care services	
Insensitive VA health care environment	Perceived stigma and negative provider attitudes	Sensitivity/cultural humility training for VA health care providers and staff
	Lack of cultural awareness and sensitivity	
	Experiences with racism	
	Unwelcoming and unfriendly clinical settings	
Lack of trust in the VA health care system	Lack of being respected	Deliver short-term "wins" for Veterans in South Los Angeles (eg, VA health services and benefits fairs, community conferences, pocket cards with functioning clinic contact numbers, transportation services resources sheet)
	Lack of timely change in response to Veterans' stated needs	
Veteran status as a barrier to accessing community services		Engaging community-based organizations to participate in Veteran-led community events

agreed that the community partners' interpretation of the data captured well that a lack of trust in the VA was a significant theme central to many of their experiences.

Results

Characteristics of the Veteran Participants

Ten African American Veterans participated in the first engagement workshop; four Veterans in the second and eight in the third. Veterans were invited to participate in as many of the engagement workshops as they could attend and/or in which they were interested in participating. Thus, some Veterans attended more than one workshop; all four Veterans in the second workshop and six Veterans in the third workshop had participated in prior workshops. Veterans attending the workshops were predominantly Vietnam era and included two women Veterans. Additionally, three female family members of Veterans participated in the first engagement workshop; two of these women participated in the second and third engagement workshops. As the Veteran engagement workshops represented the beginning of a community partnered process, Veterans were regarded and treated as equal participants in a quality improvement project, not as research subjects. We did not query individual Veterans about, or collect data on, their military service era or demographic information, apart from what they spontaneously described in the context of the engagement workshops.

Emerging Themes

We identified two positive themes: 1) Veterans have knowledge to share and want to help other Veterans; and 2) connecting effectively to VA care can result in positive experiences. We identified 10 subthemes, which were organized into three domains, or overarching themes: 1) functional barriers to accessing VA health care services (4 subthemes); 2) insensitive VA health care environment (4 subthemes); and 3) lack of trust in the VA health care system (2 subthemes). A fourth

domain, Veteran status as a barrier to accessing community services, was identified and did not have any subthemes. Relevant to challenges Veterans identified, we also report suggestions Veterans offered for improving the VA health care system and its services. Qualitative results are reported in Table 1.

Positive Themes

Veterans Have Knowledge to Share and a Desire to Help Other Veterans

"Vets have a lot of knowledge to share among each other…" one Veteran said. His sentiment was echoed by many other Veterans. They talked about how, regardless of whether their experiences with VA care had been good or bad, they could leverage their knowledge, as many described they were already informally doing, to inform and help fellow Veterans in their community. Veterans described feeling greater trust and comfort among fellow Veterans, relative to VA staff and health care providers. Veterans expressed an interest in starting a community support group "for Vets by Vets." They discussed how this could be an opportunity to come together and share their experiences with one another, and to help one another navigate VA care. Veterans also talked about developing Veteran-directed outreach to other Veterans by designing and implementing a community "drop-in" center. They described the purpose of a community "drop-in" center as a place where Veterans could connect to VA benefits and social and health care services. Another idea Veterans proposed was developing a VA-community website with useful, current and easy-to-use information and links.

Connecting Effectively to VA Care Can Result in Positive Experiences

This theme emerged from Veterans' descriptions of positive experiences with VA health care services. Notably, almost all Veterans who endorsed positive VA health care experiences also reported that connecting to services and health care involved the assistance and encouragement of someone knowledgeable about how the VA system worked. One Veteran recounted how a friend helped him re-connect to the VA. He stated that this friend walked him through the process of signing up for benefits. As a result, the Veteran was able to access VA care. Over the last several years, he reported, his experiences with VA care have been good, including the care he received from VA doctors for his liver transplant. Another Veteran stated that, since recently receiving his VA health and benefit cards, he had been receiving VA health care, and that he had no negative experiences to report about the care provided. He did, however, state that it was a difficult process to get his cards, and that it had taken him 30 years to get them. Veterans also shared that having a provider who advocates for them and follows through with providing continuity of care could have a significant impact on their health and satisfaction with care. One Veteran with prostate cancer shared that when his PSA levels started to rise, he was unable to reach his primary care doctor to obtain the necessary referrals and tests. He described his dilemma to his psychiatrist, who called him later in the day to report that she had personally spoken to the urologist and had arranged the necessary tests and follow-up appointment for the Veteran herself. He endorsed appreciation of her concern and ability to follow through.

Negative Themes

Functional Barriers to VA Health Care Services Access

Four sub-themes were related to functional barriers accessing and navigating VA health care services.

Subtheme 1: Lack of VA health care services in South Los Angeles. Veterans identified this as a major barrier to health care access and services delivery. Veterans described a strong need and desire for the VA to come to Veterans in the community where they live. They suggested that a "one-stop shop" that provided health care, social services and benefits counseling would be convenient and would increase their ability to access care. Veterans questioned why the VA could not build a clinic in South Los Angeles.

Subtheme 2: Transportation difficulties. Veterans described the challenges they face when trying to travel from South Los Angeles to VA facilities to access primary, mental health, emergency room, or subspecialty services. Many Veterans reported not having cars. Some described having significant medical comorbidities and/or disabilities

that would make taking public transportation difficult, especially given that the route to VA facilities requires multiple transfers and that transit time is 1-2 hours at a minimum, depending on traffic. Veterans relayed past experiences in which they asked friends or family members to give them a ride to the VA. The challenge, they stated, was how to get back home, especially when clinics run behind and/or clinical services take a long time to complete. Veterans described how family or friends who work and or have other commitments cannot stay and/or return to take Veterans home. Veterans suggested changing the restrictive requirements for ACCESS transportation or providing some other form of transportation.

Subtheme 3: Difficulties initiating access to VA health care services. One Veteran stated, "If you don't know the telephone extension, it's like it doesn't exist." Even if Veterans could find a telephone number for health care services, they stated that the number was often incorrect or not functioning. Veterans expressed frustration over long wait times on the phone; when they could get through, Veterans stated they still might not get answers to their questions. They reported learning more from other Veterans than from a VA-based source about where to go to initiate care and find out about services.

Subtheme 4: Difficulties maintaining access to care and navigating the services to which Veterans were already connected. Veterans described a lack of follow-up and/or ongoing monitoring by VA health care providers. One Veteran endorsed waiting for more than three months to hear about a subspecialist appointment he was supposed to have. Other Veterans relayed challenges navigating the transition from the Emergency Room (ER) to primary care and/or mental health, stating they didn't know what to do or where to go after they had been seen in the ER. One Veteran expressed dismay at variations in primary care provider continuity; he stated that seeing a different resident physician every visit resulted in fragmented care and never knowing who to contact with questions, and so he stopped going for care.

Insensitive VA Health Care Environment

Within this theme of an insensitive VA health care environment, four sub-themes emerged.

Subtheme 1: Perceived stigma and negative provider attitudes. Veterans described the discomfort they felt and the discrimination they perceived in seeking or receiving health care, particularly Veterans with dual diagnoses or chronic pain.

Subtheme 2: Lack of cultural awareness and sensitivity. Veterans' experiences with the VA health care system and among VA health care employees, included staff and providers who used inappropriate language and/or who did not demonstrate awareness of the racial and ethnic dimensions of health and health care. Veterans agreed with one participant's suggestion that VA providers and staff should receive meaningful sensitivity training.

Subtheme 3: Experiences with racism. Veterans described encountering racism, both in the military and in the VA health care system, and relayed how these experiences cultivated a sense of alienation from the VA.

Subtheme 4: Unwelcoming and unfriendly clinical settings. One Veteran described feeling invisible and ignored as he walked the halls of the main medical building of the West Los Angeles VAMC; he said no one said hello or looked at him.

Lack of Trust in the VA Health Care System

Veterans' comments were categorized into two subthemes related to lack of trust in the VA health care system:

Subtheme 1: Lack of VA health care system respect for Veterans. Veterans described not feeling acknowledged by the VA, or not having their concerns taken seriously. Some Veterans reported feeling angry and resentful, and stated they did not trust the VA.

Subtheme 2: Lack of VA health care system responsiveness. Veterans expressed frustrations over the lack of timely and meaningful change in response to widely recognized problems, long-standing concerns and consistently stated needs. Several Veterans relayed they had, in the past, been part of VA advisory groups in which they had expressed their opinions and shared their experiences. They endorsed feeling frustrated that they never heard back from these advisory groups. They asserted that not knowing what, if anything, had resulted from their time and efforts

made them feel disrespected. Veterans stated feeling "sick and tired" of talking and not being included in the process of making significant change. "We've been talking for 30 years and nothing has happened," exclaimed a Veteran. Veterans described how the lack of VA responsiveness to voiced concerns and publicly known problems within the VA health care system made it difficult for them to trust the VA and what, if anything, the VA stated it would do to address current problems. One Veteran demanded to know what we were going to do *now* to make things better. Veterans suggested organizing neighborhood health fairs where Veterans could sign up for benefits and talk to VA service providers. HAAFII staff suggested putting together a community conference to highlight Veterans' needs and share community and VA resources for Veterans.

Veteran Status as a Barrier to Accessing Community Services

The final negative sub-theme to emerge was Veteran status as a barrier to accessing community services. Veterans stated that community-based organizations and social service agencies would not help Veterans once these groups found out about their Veteran status. Veterans stated that these groups would simply refer them back to the VA. Veterans relayed that, when seeking social services in the community, they would purposefully not disclose their Veteran status out of concern they would not be offered the same services or community resources as were being afforded to non-Veteran clients.

Discussion

Veterans living in underserved areas who have disengaged from, or who are not connected to or are unable to effectively access, VA care, and who may be or feel marginalized from the VA health care system, have unique perspectives on VA services. Their perspectives and active participation are often missing from the development, implementation and evaluation of VA care, but may be critical for increasing the relevance and uptake of care innovation. We were able to engage marginalized Veterans in a research and quality improvement initiative using a CPPR approach within their home community. By partnering with a trusted local community organization, we were able to identify and work with marginalized Veterans who otherwise would have been difficult to find, reach out to and engage in partnered work. Employing a partnered approach with significant dialogue facilitation by HAAFII staff in a community-placed setting that was familiar and comfortable for Veterans may have helped support and promote honest and informative collaboration. These Veterans identified many negative, and several positive, features that characterized their VA health care. Our findings included general issues that pertain to all patients and Veterans but may be especially difficult for the community we worked with, which faces additional barriers that may include socioeconomic disadvantage, stigma and/or low trust. Examples include finding phone numbers that work, getting through on the phone, navigating services and access to care. Similar to our findings, previous studies have demonstrated that inconvenient distance from a VA health care center is a barrier for VA health services use.[24,25] Our findings included issues that were specific to the African American, urban community with which we worked, such as not having VA services located in South Los Angeles, being turned away for being a Veteran by community-based organizations in their community, and

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having worked with VA researchers in the past, without perceiving any meaningful results or follow-up. The challenges Veterans described with institutional racism and with physicians-in-training have been previously reported.[26] We report the suggestions Veterans spontaneously endorsed for improving VA services and access, some of which they expressed should arise from the VA and others which they themselves could undertake. The Veterans' perspectives provided some previously described, and some unique, insights into the challenges they face and the strengths they employ when interacting with the VA health care system and services.

Veteran and stakeholder engagement can provide direction for improvement. Despite the many challenges, such as greater time demands and sharing power with nontraditional partners, engagement carries many benefits, including: helping to direct research toward questions that matter most to stakeholders; enhancing study design by selecting outcomes that matter to end users and choosing methodologies that optimize data collection and validity; eliciting greater buy-in around implementation and dissemination; and improving research translation into clinical practice.[27,28] Moreover, there is an overarching ethical mandate for patient participation in research as a way to demonstrate respect for patients and vulnerable populations. In many communities, "research" is a loaded word that sets expectations of being examined or exploited.[18] By treating stakeholders as co-equal partners, the potential for the research process to alienate patients and communities is minimized,[28] and the ability to overcome barriers through honoring diversity and building capacity for healthy communities is maximized.[18]

Our QUERI project represents a key opportunity not only to describe a process of Veteran engagement, it also affords an opportunity to enact meaningful, more timely change. Veterans described having participated in advisory or feedback groups in the past, but that nothing came of their efforts. Because our project employs a CPPR approach, Veterans share power and responsibility as active and equal partners in a process that requires accountability, transparency and commitment from both academic and community partners; Veterans are necessarily involved from the outset to the end of the project. In our ongoing monthly Veteran meetings at HAAFII, we have activated several short-term "wins," or deliverables, which the Veterans delineated as project goals. For example, we developed a transportation brochure and pocket card outlining VA and Los Angeles County transportation resources and have distributed these materials at community events and to the VAGLAHCS Office of Community Care to be used in outreach activities. In concert with the VAGLAHCS, the Veterans co-led a community event that took place in fall 2017 for the South Los Angeles community in which they live. The event included Veteran-led cultural performances and presentations, and engaged community-based organizations and VA service and care providers to staff information booths, conduct Veteran outreach and deliver services.

Study Limitations

This exploratory project has important limitations. The number of Veterans who participated in the workshops was relatively small *(N*=10). Extant research has noted, however, that thematic saturation in qualitative studies can be achieved within a sample size of 12 participants, and sometimes as early as six.[29] We also acknowledge the possibility of selection bias. Veterans who agreed to take part in the project and attend the workshops may have been motivated to participate because they had had negative experiences with the VA. We recognize that the Veterans we describe in this article are not a representative sample of all marginalized Veterans, and that the VAGLAHCS is not representative of all VA health care systems across the country. Past work has demonstrated significant variation among Veterans Affairs hospitals and clinics along multiple dimensions, including quality of care.[30-32] Additionally, because this project engages Veterans and focuses VA health care services, our qualitative findings may not be representative of other health care settings outside of VA.

Conclusion

As health care systems, including the VA, move toward population health management, the engagement approach we employed may

inform a process for identifying and engaging marginalized stakeholders in a partnered approach to improve health care services and access.

Acknowledgments

We thank Elvira Jimenez, Nancy Hernandez, Andrea Jones, Kymberly Aoki, Zoe E. Masongsong and Malon Murphy for their invaluable assistance with project coordination. This research was funded by QUE 15-276, VA Quality Enhancement Research Initiative (QUERI) Care Coordination Program Project. Loretta Jones is funded by NIMHD 5U54MD007598.

Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Izquierdo, Ong, F Jones, L Jones, Rubenstein; Acquisition of data: Izquierdo, F Jones, L Jones, Rubenstein; Data analysis and interpretation: Izquierdo, Ong, F Jones, L Jones, Ganz, Rubenstein; Manuscript draft: Izquierdo, Ong, Ganz, Rubenstein; Statistical expertise: F Jones, L Jones; Acquisition of funding: Ong, Ganz, Rubenstein; Administrative: Izquierdo; Supervision: Izquierdo, Ong, F Jones, L Jones

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