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Perspective

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Integrating Antiracism and Life Course Frameworks in Research with Autistic Minority Transition-Aged Youth and Young Adults

Emily Hotez, PhD,[1] Shanice Hudson, PhD,[2] Kristen R. Choi, PhD, PMHNP-BC, FAAN,[3] and Alice A. Kuo, MD, PhD, MBA[1,3]

Abstract

Racial and ethnic minority autistic transition-aged youth and young adults (TAYA) experience a range of barriers to optimal health, development, and thriving. These barriers are related to challenges associated with this distinct developmental period, as well as experiences linked to their multiple marginalized intersectional identities. Currently, there is a need for additional research that can spur the development and dissemination of critical supports for this population. In the current perspective, we call on researchers to integrate two established frameworks for: (1) antiracism research (i.e., the Public Health Critical Race Praxis [PHCR] model) and (2) sensitivity to developmental transitions (i.e., the life course health development [LCHD] model). Together, the PHCR and LCHD models offer a practical guide to conceptualize research with this population. We discuss how the central tenets of these models apply to minority autistic TAYA, propose overarching recommendations to researchers, and highlight existing and promising approaches that reflect these recommendations.

Keywords: race, racism, autism, TAYA, emerging adulthood, life course

Community Brief

Why is this topic important?

There is a need to better understand racial and ethnic minority autistic young adults (age 18–28 years) through research. This article will help researchers study this population and emphasizes applicability and action for health care providers, policymakers, and other contributors.

What is the purpose of this article?

This article discusses two theories from the research and how they might be helpful for racial and ethnic minority autistic young adults. The first one—called the ''Public Health Critical Race Praxis Model''—emphasizes the need to consider the important role of race and racism in the lives of autistic racial and ethnic minority autistic young adults. The second one—called the ''Life Course Health Development Model''—emphasizes that young adults experience the world differently from adolescents and older adults, and it is important to consider these differences when supporting this population.

[1]Department of General Internal Medicine and Health Services Research, David Geffen School of Medicine, University of California, Los Angeles (UCLA), Los Angeles, California, USA.
[2]Hood Medicine Initiative, Inc., Indianapolis, Indiana, USA.
[3]Department of Health Policy and Management, Fielding School of Public Health, University of California, Los Angeles (UCLA), Los Angeles, California, USA.

What personal or professional perspectives do the authors bring to this topic?

Dr. Hotez's research focuses on supporting autistic individuals across the life course—particularly young adults—as well as supporting other communities who often experience discrimination or stigma. Dr. Hudson is an expert in racial equity and founder of the Hood Medicine Initiative, which seeks to improve the health of Black individuals and communities. Dr. Choi is a child and adolescent psychiatric nurse and researcher with expertise in autism and equity across the life course. Dr. Kuo is the Chief of Medicine-Pediatrics at University of California, Los Angeles and has an expertise in supporting autistic young adults in her clinic and in her research. All authors have a personal lived experience or connection to the topic of this article.

What is already known about this topic?

The transition between adolescence and adulthood (age 18–28 years) is often a time of significant change in health care, education, employment, and in relationships. This time may be particularly difficult for autistic individuals who experience unique barriers—including stigma and discrimination—in these areas. Racial and ethnic minority autistic young adults often experience even more challenges, as they may encounter additional barriers related to accessing and utilizing important services and supports. They may also experience additional discrimination and stigma related to racism.

What do the authors recommend?

We recommend that researchers study the specific ways in which race and racism can affect autistic individuals during the important period of young adulthood. We also recommend that researchers study their experiences in health care, education, employment, relationships, and in other circumstances and emphasize application and action for nonresearchers. Researchers can ensure that their work is helpful to racial and ethnic minority autistic young adults by working with this population in developing their studies.

How will these recommendations help autistic adults now or in the future?

We hope that these recommendations will lead to better studies, which will lead to the creation of more helpful supports and services for this population.

In the current Perspective, we call on autism researchers to apply two established frameworks for: (1) antiracism (i.e., the Public Health Critical Race Praxis [PHCR] model) and (2) developmental science (i.e., the life course health development [LCHD] model) in their study of autistic racial and ethnic minority transition-aged youth and young adults (TAYA). To date, failure to prioritize and apply principles from these equity-focused frameworks has limited the extent to which research and practice effectively address the significant health inequities experienced by autistic individuals across the life course.[1,2] Together, the PHCR[3] and LCHD models[4] offer a necessary blueprint for conceptualizing research with this population and informing equity-driven action. In this article, we provide a foundational literature review; discuss how the central concepts of these models apply to minority autistic TAYA; propose overarching recommendations to researchers—as well as other professionals, including practitioners—and highlight existing and promising approaches that reflect these recommendations.

As context, the current article is grounded in the principle of *intersectionality*, which emphasizes the importance of interrogating power imbalances, social identities, stigma, and structural oppression among populations with multiple marginalized identities,[5–7] including racial and ethnic minority autistic TAYA. In alignment with intersectionality, the experiences of this population as both racial and ethnic minorities and neurodivergent individuals cannot be conceptualized through a lens that separates these statuses.[5] Therefore, intersectionality as an organizing framework, analytic strategy, and action-oriented guide—described in detail in the literature in terms of its origins and intended applications[7]—is central to all aspects of our article. Notably, intersectionality in autism has been increasingly recognized, including in a Special Issue in *Autism in Adulthood*.[8] The current article aligns with these efforts and extends these conceptual and empirical analyses by integrating complementary theoretical models that can provide further nuance and facilitate translation efforts.

Introduction

The transition between adolescence and adulthood (age 18–28 years)—often referred to as transition-age or emerging adulthood—is a distinct developmental period[9] marked by change and instability in health care, education, employment, and interpersonal domains.[10] During this time, TAYA typically develop a stronger sense of identity and take steps toward independence in work, education, relationships, and daily life. The adult transition period brings possibility and opportunity but may also bring instability. Due to the

dynamic nature of this developmental period, it is often considered a time of both risk and opportunity from a health perspective and has been conceptualized as a particularly optimal time for intervention.[11] In autistic individuals, this period is often accompanied by increasing rates of physical and mental health challenges due to inequities in health care and society.[12–16]

For autistic TAYA, health challenges are due to a range of factors, including experiences of *minority stress* and its consequences. Indeed, according to the minority stress model, marginalized individuals—including autistic adults—may experience additional stress burden beyond the overall life stress experienced by the general population.[17] Autistic adults may rely on *camouflaging* as a coping mechanism—defined as utilizing behavioral and cognitive strategies to mask autistic traits and appear more ''typical''[18,19]—which has been found to exacerbate negative health outcomes by increasing stress.[12,20,21] Autistic TAYA also experience a ''services cliff'' at the transition from the pediatric to adult systems of health care, where there are significantly fewer services and resources available.[22–24] The services cliff results in fragmentation—or full dissipation—of important services,[25] during a time when the need for these supports is potentially highest. Together, interpersonal stress and structural disadvantage contribute to worsened health outcomes for TAYA.

Health and health care challenges are particularly pronounced for *racial and ethnic minority* autistic TAYA. Inequities for racial and ethnic minority autistic TAYA can be traced to a range of factors, including lack of access to a timely and accurate autism diagnosis in childhood, a dearth of strengths-based neuro-affirming services across the life course, and a lifetime of discrimination and marginalization across educational, health care, and policy sectors.[16,26–34] Indeed, individuals who align with *multiple* marginalized identities—such as racial and ethnic minority autistic TAYA—experience compounded minority stress[35] due to ableism, racism, and collateral health consequences from victimization, discrimination, psychological distress, low self-efficacy, and inadequate health care access.[36,37] There is, therefore, a need for additional efforts that can prevent and address inequities for this population.

There is limited research on autistic TAYA, which inhibits the capacity to spur the development of supportive interventions and services for this population. Shortcomings are due, in part, to a lack of autism research in alignment with appropriate theoretical and methodological frameworks that can account for both racial and ethnic and developmentally specific experiences. This gap prevents the advancement of research, policy, and practice and the responsiveness of these sectors to the specific needs of autistic racial and ethnic minority TAYA. This article seeks to address this gap by elucidating opportunities to link these frameworks with systems that can support this population.

PHCR Applied to Autistic Minority TAYA

Although research with autistic populations is becoming increasingly aligned with social justice movements—particularly the neurodiversity movement[17]—few studies seek to integrate practically oriented, critical race theory (CRT)-focused models of antiracism in the study of autism. CRT, which has been applied in public health research,[3,38] is a movement focused on racialization, marginalization, and the role of scholars in producing knowledge about societal inequities. The PHCR offers a semi-structured process for applying CRT, specifically related to conducting research that remains attentive to issues of both racial equity and methodological rigor.[3] PHCRs key concepts include four ''focuses,'' which represent the main phases of the PHCR process (described in the subsequent sections).

LCHD Applications to Autistic Minority TAYA

The LCHD framework explains how individual- and population-level health trajectories are determined by interactions between biological and environmental factors during key developmental windows throughout the life course.[4] As in PHCR, the LCHD framework seeks to shift from a deficit-oriented medical model approach toward an approach that emphasizes virtuous cycles[39]; seeks to optimize health and well-being trajectories; and adopts a proactive and tailored approach to health care.[40,41] There are, however, few LCHD studies applied to autistic populations. Although federal investments have supported portfolios of research focused on health care transitions for autistic TAYA,[24,42] there remains a need for additional efforts in alignment with this model and its three central principles (described in the subsequent sections). The limited number of studies with an LCHD approach impedes the extent to which research can support autistic individuals during this critical developmental window and throughout the life course.

Applications of PHCR and LCHD to Autistic Minority TAYA

In the following section, we define and apply the PHCR and LCHD frameworks for autistic minority TAYA and describe applications to broader autistic populations as well. In alignment with intersectionality, our discussion broadens the focus of PHCR beyond racism to encompass experiences of ableism, discrimination, rejection, marginalization, and exclusion (referred to broadly as *stigma*) to reflect the varied experiences of heterogeneous autistic populations. In the current study, we adopt this broad definition of stigma to account for factors that can occur at both interpersonal and systemic levels and compound across the life course.[28,30,41,43,44]

PHCR focus 1: contemporary racial relations

This focus area emphasizes that although racism is permanent within racialized societies, the ways in which racism *operates* changes over time.[3] This focus area can be readily applied to research with autistic minority TAYA, given that this population experiences unique forms of stigma relative to other populations, autistic populations during different developmental periods, and previous historical cohorts of autistic minority TAYA. As an example, research shows that autistic TAYA highly value[45] and engage with social media,[46] and usage may have increased during the COVID-19 pandemic.[47] Masking or camouflaging on social media has been cited as a means of stigma avoidance.[48,49]

This focus area can be extended beyond social media and applied to a range of contexts increasingly applicable to autistic TAYA. As an example, given that more autistic

TAYA are enrolling in postsecondary institutions[50] and employed in vocational settings,[51] these contexts may be important to investigate in future research. There remains a need to investigate racial and ethnic minority autistic TAYA in health care settings, in their roles as consultants or community partners in research,[52] and in other contexts where stigma may be a barrier.

PHCR focus 2: knowledge production

This focus area seeks to understand how racialization may shape a project or, conversely, how the project may reinforce existing beliefs about racial groups or phenomena.[3] Even with the most rigorous methods, research as a form of knowledge production may not be free from bias or inherently objective. Racialization often influences research, our understanding of existing knowledge, and the tools of research. In alignment with this area, autism researchers can prioritize ensuring that the research methods utilized do not further marginalize participants and that marginalized voices are deliberately centered in knowledge production. This requires a *strengths-based* approach[53]—rather than relying on a *deficit-oriented* lens—in the framing of research questions and in the conceptualization of methodology. Applying a strengths-based approach may simply involve reframing questions to reflect what autistic individuals who are also racial and ethnic minorities *can* do—rather than what they cannot do—or aligning methods with frameworks that view autistic individuals in a positive and enabling light (e.g., the Triad of Strengths framework).[54]

Considering how racialization shapes knowledge production requires challenging existing deficit-based narratives about this population.[55,56] In alignment with a strengths-based approach and the need to challenge existing racialized narratives, especially of Black autistic TAYA, researchers can focus on how their potential participants' sensory preferences, special interests, and action capabilities can guide the methodological design process.[54] Researchers can refer to the AASPIRE Practice-Based Guidelines for the Inclusion of Autistic Adults in Research Study Participants[57] for specific guidance regarding making research more inclusive and accommodating for autistic individuals.

Researchers may also apply participatory and community-partnered research approaches to center marginalized voices in knowledge production, especially those from autistic TAYA of color who have been historically underrepresented in research.[58,59] For example, autistic individuals, their families, and service providers have been previously engaged using participatory approaches to set research priorities.[60,61] When these groups are asked to define their own research priorities, multiple studies indicate that they wish to prioritize (1) action-oriented research that will result in real-world changes to their lives and (2) research across the lifespan.[60] These priorities may differ from those of funding entities, policymakers, and health or social service organizations (e.g., evident due to the overemphasis on autism in childhood or limited focus on racial/ethnic minorities).[62]

PHCR focus 3: conceptualization and measurement

This focus area prioritizes ensuring that measurement is *context-specific*, in that it assesses key constructs relevant to specific situations and circumstances for participants. Context-specific measurement is important because racism and ableism function differently depending on the place, time, and context.[3] There has been limited research to develop, refine, or test a robust set of measures and conceptual frameworks that capture the experiences of both racism and ableism. Recent publications, however, have explored how racism and ableism intersect and how both forms of oppression may be conceptualized in research.[63–65] In applying this focus to autistic populations, researchers can assess how racial stigma occurs in participants' daily lives, rather than simply documenting its general occurrence.

Furthermore, researchers can identify manifestations of structural racism (e.g., in educational or health care settings) or racism intersecting with ableism. The experience of racism and ableism together may be conceptually distinct from other experience alone, and developing tools, measures, and frameworks to capture this experience could advance equity-focused interventions. Conceptualizing race as a risk for exposure to racism, rather than as a risk factor in and of itself, is one specific PHCR strategy that may be used in research, along with assessing intersectional identities and conceptualizing links to broader systems of oppression.

In practice, researchers can assess the specific ways in which stigma may surface in a particular context. This was demonstrated in recent research that aimed to document the ways in which structural discrimination toward autistic individuals may surface within large, national funding organizations.[66] In addition to conducting a systematic review of NIH-funded studies, the researchers analyzed conversations with program officers, language within funding calls, and specific eligibility criteria, among other aspects of the funding process. Findings revealed a lack of focus on improving relevant physical health conditions through interventions, programs, or services for autistic adults in funded projects. This research elucidated specific instances of stigma in federal funding streams, which allowed for findings to more seamlessly translate into actionable next steps for increasing equity for this population.

PHCR focus 4: action

This focus area centers on the importance of actually *utilizing* research findings to address inequities,[3] which is also a critical feature of intersectionality more broadly.[5–7] A recent review found that when autistic individuals and their family members have been asked to prioritize research topics, they consistently wish to see more research that can result in real-world changes to their daily lives.[60] There are a range of specific action steps that may arise from production of new knowledge under a PHCR framework applied to autistic racial and ethnic minority TAYA. These include expanding the vocabulary and language utilized to discuss the intersection of racism and ableism; telling stories of those living at the intersection of racism and ableism, thereby centering the margins; developing and testing new interventions that can close disparities in health care access or health outcomes; adapting existing interventions for autistic TAYA; and challenging injustices that affect autistic TAYA of color in schools, health systems, places of employment, and policy.

Tangible examples of potential actions include iteratively improving data collection materials and protocols by collaborating with the focal populations in research, using the

created materials in subsequent research, and promoting uptake of these tools across the field. As an example, researchers and autistic individuals may collaborate on an interview protocol about experiences of stigma, and this protocol may be subsequently deployed in other studies that seek to capture stigma. Indeed, the advantages of participatory methods in autism research are well supported.[67] Future efforts should endeavor to increase the uptake and implementation of materials and methods developed through participatory processes.

LCHD principle 1: timing

This principle is in reference to the finding that *timing* of exposure changes how a particular risk or protective factor affects health.[4] In autism research, this may entail conceptualizing the transition to adulthood as a *sensitive period* when an individual is particularly susceptible to both risk and protective factors. This can ensure that intervention efforts concentrate on developmental periods when they can be most impactful. Sensitive developmental periods have traditionally been conceptualized as occurring in early childhood,[68] yet contemporary developmental science suggests that periods of transitions and instability—particularly adolescence and emerging adulthood—are pivotal opportunities for intervention.[69,70] There is a well-documented need for autism research beyond childhood, which is a central gap addressed by *Autism in Adulthood*. This line of research is poised to be particularly impactful given the growing body of research that indicates that autistic TAYA require more support across systems and sectors.

LCHD principle 2: chains of risk

This principle refers to the finding that exposure to a particular type or quality of adversity leads to exposure to another.[4] This patterning results in a *chain*, or an accumulation of risk factors. The inverse of this principle also applies; investigating chains of *protective or promotive factors* (i.e., virtuous cycles) can be advantageous for identifying leverage points for interventions.[39] This principle is critical for autistic populations, for whom anticipated or experienced stigma can lead to camouflaging: deploying specific behavioral and cognitive strategies to appear more ''typical.''[71] Camouflaging, in turn, leads to low well-being, self-esteem, and quality of life; high distress, anxiety, depression, and suicidality; and delayed diagnosis and compromised health care in autistic individuals.[20,72] The emerging research in this area indicates that stigma-related chains of risk and protective factors are critical to capture for autistic populations, particularly TAYA who have well-documented experiences with camouflaging.

LCHD principle 3: a multilevel approach

This principle emphasizes that the study of complex challenges requires analyses at the individual, interpersonal, and systemic levels.[4] A multilevel approach to research would include assessment of proximal and distal contextual factors that potentially serve as key facilitators or barriers for individuals or groups. Research that seeks to understand autistic individuals' experiences in postsecondary institutions, for example, can include interviews with students, family members, peers, faculty members, and administrators as well as analysis of institutional and structural factors in schools and communities. The authors of this perspective are currently forging researcher–educator partnerships with Historically Black Colleges and Universities and other minority-serving institutions to carry out a multilevel research study of autistic minority TAYA.

These efforts are supported by the Health Resources and Services Administration Autism Transitions Research Project (ATRP),[24] which is supporting a portfolio of research on autistic TAYA. Through this project, we will be investigating both barriers and facilitators to postsecondary success among this population across individual and institutional levels. Autism researchers can adapt a multilevel approach in their own work by assessing multiple relevant contributors, integrating mixed methodologies that capture interpersonal and environmental factors, and developing research questions that conceptualize the individual as embedded within multiple interrelated systems, among other strategies.

An Integrated Approach

The focal theoretical models in the current article can be readily integrated in research, practice, and policy. Efforts to do so are underway, in response to calls in the field for more attention toward Black autistic adults,[58] for example. Indeed, the ATRP study described above is a response to these efforts and is an example of centering racial and ethnic minority autistic individuals in research and applying a distinct developmental lens. The intersection of these models, however, can also be applied in other contexts. An emerging priority in medical education and training, for example, centers on aligning clinical practice with principles of intersectionality.[73] Enhancing the capacity of the next generation of health care providers to provide an individualized and tailored approach (i.e., a *precision medicine approach*) to clinical encounters can ensure that providers are supporting the multifaceted needs of this population.[74]

Overarching Recommendations for Research with Autistic Minority TAYA

Considering the applications of PHCR and LCHD to research with autistic minority TAYA, we propose several overarching recommendations for the field. We simultaneously present examples of promising approaches that reflect these principles.

Recognize the role of interpersonal and structural stigma: including racism and ableism—in the lives of autistic minority TAYA

Racial and ethnic inequities in autism are well documented,[75] yet less understood are the lived experiences of racism and ableism of autistic TAYA with multiple marginalized identities. While these forms of discrimination are potentially more easily conceptualized at the interpersonal level, they are potentially more pernicious and impenetrable at the structural level. As an example, health care practices and policies that make health care less accessible and inclusive may—often inadvertently—prevent autistic individuals from receiving critical and life-saving services and supports.

Investigating the myriad types of racism and ableism is critical due to the well-established findings that support that

racism and ableism directly contribute to health inequities. Efforts to better understand these experiences are underway, including within *Autism in Adulthood*,[76] yet there remains a need to translate findings into tangible improvements to the systems and sectors that serve autistic individuals. In emerging and future efforts, particular attention should be paid to intersectionality to ensure that research reflects the vast heterogeneity within autism. To account for intersectionality in research, Lopez (2022) provides actionable strategies for capturing and responding to the heterogeneity inherent in autistic populations across contexts. These strategies include, for example, tailoring accommodations based on individualized needs, rather than on overarching assumptions.[6] These recommendations can be easily extended to health care contexts to ensure that the wide-ranging needs of autistic individuals are being met.

Ensure research findings will be relevant to the lived experiences of autistic minority TAYA

The field offers several strategies in support of this goal, including designing studies with *a priori* attention to cultural, familial, and individual contexts.[77] This can enrich the validity of findings in research and enhance clinical practice.[77] This recommendation can also ensure that research is responsive to specific experiences of this population (e.g., stigma). In the case of stigma, this can be achieved by assessing (1) the occurrence of stigma in relation to relevant developmental and situational contexts for autistic minority TAYA, as well as (2) types of stigmas that lead to chains of risk and protective factors. Indeed, there is a burgeoning body of research on camouflaging as a coping mechanism for anticipated or experienced stigma.[12,19,20,71,72] This research has spurred the development of data collection tools that can facilitate this area of inquiry.[19] Future efforts should expand on this research and identify additional chains of risk from experiences of stigma.

Collaborate with autistic minority TAYA in all facets of research

In practice, this may entail collaborations in (1) the development and implementation of strengths-based data collection measures, and (2) the dissemination and translation efforts, to promote uptake of measures within the field. To be sure, advancements in participatory research are ongoing.[52,78,79] At the same time, autism researchers report myriad challenges in conducting effective participatory research, including ambiguity about how to implement such methods and limited resources to do so.[80] With increased development and dissemination of guidelines for researchers to conduct participatory methods,[52,57] we look forward to autism researchers' increased uptake of participatory methods, as well as systemic and cultural efforts that can facilitate these capacities.[80]

Seek to move beyond the documentation of experiences of stigma toward action-oriented research

It is well documented that autistic individuals experience stigma, discrimination, victimization, and rejection across the life course.[16,26–34] Advancing this line of research will require that future studies (1) capture the developmental and situational nuances of how and when these experiences occur, and (2) conceptualize these experiences as daily occurrences embedded in individuals' developmental ecosystems. Indeed, research is moving in this direction, with qualitative approaches yielding particularly important insights in this area.[28] Importantly, in alignment with PCHR and in the resounding call in the field for more action taken toward promoting equity for autistic individuals,[81] future efforts should also seek to maximize the translation of findings to practice and policy. There is potential for funding agencies to emphasize the need for proposals to identify leverage points for interventions that will emerge from this type of research. This will ensure that the research is poised to spur critically needed action.

Align research questions and methods across multiple levels of analysis

Multilevel analysis may include assessments of (1) interpersonal experiences and (2) structural factors—both proximal and distal—that are key to addressing the research questions and providing contextual information for interpreting results. In autism research, this may require research with diverse contributors (e.g., individuals with lived experience, service providers, educators, health care professionals); deployment of mixed methodologies to assess interpersonal and environmental factors (e.g., interviews combined with environmental scans); and collaborating with autistic individuals to ensure that measurement tools and protocols will capture multiple levels of analysis.

Conclusions

The current study was a collaboration among interdisciplinary researchers and practitioners with both professional and personal investments in racial and ethnicity minority autistic TAYA. This effort was limited by a lack of collaborating autistic TAYA among the coauthors. Future efforts should prioritize addressing this gap. Taken together, our article emphasizes that autism research—and its capacity to translate into supportive interventions and services for this population—remains limited in part due to lack of alignment with appropriate theoretical and methodological frameworks, including the Public Health Critical Race Praxis and the LCHD framework. In the current perspective, we call on researchers to integrate the PHCR practice model[3] and LCHD approaches[4] when conceptualizing research with this population. We discuss how the central concepts of these models apply to minority autistic TAYA, propose overarching recommendations to researchers, and highlight existing and promising approaches that reflect these recommendations.

Authorship Confirmation Statement

E.H.: Funding acquisition, conceptualization, writing—original draft preparation, writing—reviewing and editing. S.H.: Writing—original draft preparation, writing—reviewing and editing. K.C.: Funding acquisition, writing—original draft preparation, writing—reviewing and editing. A.A.K.: Funding acquisition, supervision.

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Address correspondence to:
Emily Hotez, PhD
Department of General Internal Medicine and Health Services Research
David Geffen School of Medicine
University of California, Los Angeles (UCLA)
911 Broxton Avenue
Los Angeles, CA 90095
USA

Email: ehotez@mednet.ucla.edu