



Technical Brief Disposition of Comments Report

Research Review Title: Strategies for Improving the Lives of Women Aged 40 and Above Living With HIV/AIDS

Draft review available for public comment from April 19, 2016, to May 19, 2016.

Research Review Citation: Adam GP, Di M, Cu-Uvin S, Halladay C, Smith BT, Trikalinos TA. Strategies for Improving the Lives of Women Aged 40 and Above Living With HIV/AIDS. Technical Brief No. 29. (Prepared by the Brown Evidence-based Practice Center under Contract No. 290-2015-00002-I.) AHRQ Publication No. 16(17)-EHC040-EF. Rockville, MD: Agency for Healthcare Research and Quality; November 2016.
www.effectivehealthcare.ahrq.gov/reports/final.cfm.

Comments to Research Review

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Comments on draft reviews and the authors' responses to the comments are posted for public viewing on the Web site approximately 3 months after the final research review is published. Comments are not edited for spelling, grammar, or other content errors. Each comment is listed with the name and affiliation of the commentator, if this information is provided. Commentators are not required to provide their names or affiliations in order to submit suggestions or comments.

The tables below include the responses by the authors of the review to each comment by a peer reviewer or member of the public that was submitted for this draft review. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	General comments	This technical brief makes it clear that the state of science in this area (interventions for older HIV-infected women) is unclear. To some extent that result reflects a bit of a mismatch between the mission of a technical brief (“It is intended to provide an overview of key issues related to the technology/intervention such as current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention”) and the subject at hand. The dispositive word in the definition above is “intervention.” In area under consideration in this brief no individual intervention whose efficacy can be measured is ever articulated. In its stead several possibly overbroad problems are listed as major questions to be addressed, and then an array of potential interventions are considered, each designed to solve a narrow component of the overall problem.	Thank you. The reviewer makes a good point about the limitations of the format. However, we cannot make any changes.
Peer Reviewer #1	General comments	Transgender women are given special consideration as a group because their needs are unique, and they are marginalized. However, whether they are the only group that fits that description (e.g., other groups that face similar, if not identical problems, would include Native Americans, Muslim Americans, and Asians) is unclear, and the authors never even offer a guess regarding the magnitude of the problem of older transgender HIV-infected women. Yet one of the four vignettes includes a transgender woman, and transgender women serve as a point of emphasis throughout the document, serving as a surrogate for all marginalized groups. If they are to have that prominent a role in this work, then some comment about the extent of the problem is warranted.	We have now edited the report to add comments in the background and discussion. We believe that the exposition in the revision is more balanced.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	General	This technical brief was a little challenging to review because it was not really focused on an intervention or technology- instead it was focused on a population with specific health needs. The use of a key informant group and the inclusion of patient stories were both helpful, especially since the evidence base for the guiding questions was so sparse. The findings from the limited available literature were clearly stated. I would have liked to see a little more detail in the final section on where to go next with this important health problem and some more ideas of research priorities.	We have expanded the Next Steps section with input from this reviewer and others.
Peer Reviewer #3	General	Well written and researched review on women aged 40 and above living with HIV/AIDS in the U.S.	Thank you.
Public Reviewer #1 (Martina Savedra)	General	<p>In order to be culturally competent, the definition of transgender women should preferably read, people who were assigned male at birth but identify as women instead of people who were born male but identify as women. This is the definition preferred by many organizations that work with transgender individuals including Gay & Lesbian Alliance Against Defamation (GLAAD).</p> <p>It would be beneficial to partner with the Centers for Disease Control (CDC) to ensure that data reported is relevant to the population instead of consistently reporting "data not readily available".</p>	<p>We have made these wording changes: This work aims to identify and characterize the empirical studies that provide information on strategies for the holistic management of older women, including transgender women (persons who were assigned male sex at birth but identify as women), living with HIV.</p> <p>In terms of providing data, we are limited in this report by what is already reported or published by the CDC, as we do not have access to their raw data.</p>
Public Reviewer #3 (Vickie Lynn)	General	Change HIV-infected population to population living with HIV; transgender women to women who identify as transgender; HIV Infected to living with HIV; were newly-infected to contracted the virus; sexually active older people to older people who are sexually active; aging women to women who are aging; infection to transmission	We have made these changes throughout the document.

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Peer Reviewer #1	Background	<p>1. The background section was concise yet generally thorough. A few clarifications might have been useful. The basis for the use of age 40 as the border between young and old (those covered in this brief) is never justified. It is not the usual boundary of reproductive age, nor does it relate to the average age of menopause. Also, they bemoan the fact that women have to travel from one specialist to another (bottom page 8), suggesting a need to put various services together. In fact arguments for co-located services for women go back at least a quarter of a century.</p> <p>2. More importantly where I feel this section falls a bit short is in fulfilling the mandate to “adequately describe the clinical problem that the new intervention is meant to address and discuss current medical practice as it relates to the clinical problem.” The problems enumerated in this section are too diffuse to easily lend themselves to any one, or even small series of, intervention(s).</p>	<p>1. Thank you. This was the age limit that was chosen by the Office for Women’s Health, who commissioned the report. The age limit is operational.</p> <p>2. Thank you. This is, as the reviewer points out, not a typical technical brief, but the Office for Women’s Health commissioned the report in order to prioritize their research portfolio.</p>
Peer Reviewer #2	Background	The background section highlights several important issues about the scope of the problem of women with HIV over the age of 40 in the US.	Thank you.
Peer Reviewer #2	Background	The authors should acknowledge the differences in the proportion of women with HIV in different part of the US. In addition, while it is mentioned that lower economic status is associated with race- more information on the overall lower socio-economic status of women with HIV should be highlighted in the background section. This is especially important as the report addresses services for women and these clearly vary based on insurance status as is noted later.	We have added this information in the background section of the report: HIV rates vary widely by geographic location, with the highest rates of diagnosis in the District of Columbia (82.9%), Illinois (44.9%, Chicago only), and Georgia (23.2%). ¹ In addition, HIV rates are highest among women living in areas where more than 21 percent of residents were below the federal poverty level. ¹
Peer Reviewer #3	Background	Appropriately researched and superbly written.	Thank you.
Public Reviewer #2 (Laura Cheever)	Background	Please clarify if "this" refers to older women or any older populations. In “Thus, the management of this population who live with HIV /AIDS represents a relatively new challenge”	We have clarified this sentence: The management of all older people who live with HIV represents a relatively new challenge, and we are still constructing the empirical evidence-base that will inform it.

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Public Reviewer #2 (Laura Cheever)	Background	Define "older" and "younger". There is also reference to "middle" age groups. As it stands, this is not correct as women can contract the infection at any age and not distinctly "younger" and "older" ages.	We have added a definition for older: Already, it is well understood that the population of older people who live with HIV (for this report, all people over the age of 40) is heterogeneous We have also clarified elsewhere in the background section.
Public Reviewer #2 (Laura Cheever)	Background	These data are available by doing calculations within the surveillance tables: "although a breakdown by gender is not readily available."	We have double checked that one cannot extract statistics in the subgroup defined by age category and other characteristics, because only age at diagnosis is reported.
Public Reviewer #2 (Laura Cheever)	Background	Some burden also lies with providers who may not initiate discussions about HIV with their older patients due to their own implicit biases, assumptions, and/or comfort speaking about sexual health.	We have added this language: Possible explanations include that older people who are sexually active may be less aware of their risk; may underestimate the likelihood that their partners can have HIV; may be more likely to engage in unprotected sex (because pregnancy is not an issue); and may be less likely to discuss sexual health with their doctors than younger people. ⁶ In addition, providers may not offer HIV testing as readily to older female patients, due to their own implicit biases, assumptions, and/or comfort speaking about sexual health.
Public Reviewer #2 (Laura Cheever)	Background	Please clarify if older women living with HIV are more likely to be depressed and lonely than their HIV-uninfected counterparts, or whether this applies to all older women.	We have added information to clarify this: Depression in HIV-infected clinic populations has been found to be two to three times higher than in general community populations, and as much as four times higher among women living with HIV/AIDS than in HIV-seronegative women.
Public Reviewer #2 (Laura Cheever)	Background	Also impacts remaining engaged in HIV care: "and may prevent women from disclosing their HIV status or from seeking HIV care"	We have added this language: Stigmatization can contribute to depression and worry, negatively affecting quality of life, and may prevent women from disclosing their HIV status or from seeking or remaining engaged in HIV care

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Public Reviewer #2 (Laura Cheever)	Background	Please clarify with what "low" transmission is compared. Also, please use another term other than "lesbian sex"	We have changed this language to: Although HIV transmission is generally considered to be low risk in unprotected lesbian sexual activity
Public Reviewer #3 (Vickie Lynn)	Background	Although HIV transmission is generally low after unprotected lesbian sex. Change to Although HIV transmission is generally low during unprotected lesbian sex	We have changed this language to: Although HIV transmission is generally considered to be low risk in unprotected lesbian sexual activity
Public Reviewer #4 (Ivy Turnbull)	Background	The data provided in the introduction states: While in its early years the epidemic affected primarily the male and the young, nowadays the HIV-infected population is approximately 24 percent women and its age composition has shifted. Upon closer examination of the data it can be argued that forty-eight women died from AIDS from 1980-1981 and that those women were more likely between the ages of 15 and 44 years. Furthermore, during 1984 through 1995, the proportion of women with AIDS cases continued to rise from 6 percent in 1984 to 19 percent in 1993; and that by the end of 1995, a total of 71,818 women with HIV/AIDS had been reported to the CDC and that by 1998, HIV/AIDS was the third leading cause of death among Black women ages 25-44. This data is significant as it provides a more detailed picture of the epidemic in this particular population and should be included in the technical brief.	We decided not to expand on the details proposed by the reviewer, because the focus of the report is different. We have checked that the statistics we report are accurate.
Public Reviewer #4 (Ivy Turnbull)	Background	The introduction also references transgendered women but there is no specific data provided relative to transgendered women over 40 living with HIV/AIDS. A Technical Brief focusing specifically on this population could be drafted as the issues and challenges relative to care among this cohort are viewed differently than those among cis-gendered women	Thank you for this comment, but this is beyond the scope of the current project.

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Public Reviewer #4 (Ivy Turnbull)	Background	<p>Women living with HIV have lower rates of survival and viral suppression compared to men. However, there was little on effective behavioral and biomedical interventions with a particular focus on HIV positive women over 40 and an complete and in-depth assessment to examine the gender disparities and the social determinants of health, including structural factors that make women vulnerable to HIV.</p> <p>There is little information provided in the Technical Brief on the care and management of HIV-positive pregnant women. As women continue to get pregnant at 40 years or over, in some cases, information on the counseling needs, services and support needed to prevent mother-to-child transmission should also be included.</p>	Thank you for this comment, but this is beyond the scope of the current project.
Public Reviewer #4 (Ivy Turnbull)	Background	<p>Due to advances in combination antiretroviral therapy 70% of people living with HIV will be over the age of 50 by the year 2020. Despite these advances, women over 50 living with HIV face challenges in health literacy that can interfere with the management of their HIV disease. Further information should be included in the brief on the importance of health literacy for the woman as well as for the workforce of providers within the context of HIV management and better health outcomes.</p>	<p>We have added the following to the end of the background section: Education efforts are required to improve the health literacy of woman living with HIV/AIDS, as well as for the workforce of providers to improve HIV management and better health outcomes.</p>

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Public Reviewer #4 (Ivy Turnbull)	Background	<p>As the management and care of HIV-positive women 40 and over needs to be comprehensive, coordinated and culturally competent, the following areas might also warrant further examination for inclusion into the Technical Brief:</p> <ul style="list-style-type: none"> • Cultural barriers, myths, beliefs about being sexually active and over 50? • Focus on programs which provide primary medical care and psychosocial services to women, as well as models created for the management of HIV-positive pregnant women 40 years and older. • There should be a thorough examination of other related issues affecting women such as substance use versus substance abuse as many women use substances to self-medicate when experiencing anxiety and/or depression. • Expand upon workforce development and education in the brief as well as include additional examples of best practice models such as “collaborative care teams” and “interdisciplinary care teams” and models which incorporate geriatricians and HIV disease specialist. • Examine the care continuum or treatment cascade—what are the numbers for women over 40 and identify any differences based on geographic location and the service delivery systems within a given area. • Examine points of contact within care and prevention-to further address the need for comprehensive, coordinated systems of care for women over 40 and above with HIV/AIDS. • Explore additional research studies, (if any) currently conducted that examines women over 40 and above living with HIV/AIDS relative to the progression of the disease and its correlation to aging. 	<p>Thank you for your thoughts. These are all important points that were included in our search and not explicitly excluded in screening, but studies on these topics may have been excluded because they did not meet other inclusion criteria.</p>

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Peer Reviewer #1	Guiding Questions	<p>While the guiding questions are encompassing they are occasionally ill-defined, and that may confound attempts to design, or even perform a search for, appropriate interventions. This is evidenced by the very first bullet on page 9. They authors want to know the impact of various healthcare services, programs and policies on various subgroups of women. However, absent a well-crafted definition of “impact” it’s hard to know how to move forward toward an answer. Is the impact better QOL, longer life, better medication adherence, less impecunious circumstance? In contrast the second bullet sets a more modest goal, but one that is important, and one that is hypothetically answerable (what services keep women in healthcare). The fourth bullet is a bit confusing (What are the barriers facing women living in their initial or continued engagement with a program). The fifth bullet again would be clearer if the key outcome (“stay” in the continuum of care) were defined. Is that most visits, occasional visits, every visit? I realize briefs are not meant to be definitive documents, but the clearer the questions, the more clearly directed the search for answers. The key outcome in Area two is also not optimally defined (women’s well-being). The possible meanings are encyclopedic in scope. The final bullet on page 9 seems to be seeking a universal tool that is reliable for the “entire spectrum of severity.” Given this enumeration of objectives, it could have been predicted before the search began that it would be difficult to have success.</p>	<p>Thank you. You make a good point that the guiding questions are generic. They were provided by the Office for Women’s Health, and were used to define the three areas of interest for the report, which will be used to prioritize future research.</p>

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Peer Reviewer #2	Guiding Questions	<p>The guiding questions are grouped into 3 complementary areas.</p> <p>1- evaluates strategies for engaging women with resources</p> <p>2- evaluates the impact of insurance status, specifically ACA on access to services</p> <p>3-evaluates the role of comorbidities and access to services for treatment/prevention on overall outcomes</p> <p>It would be good to have mental health needs addressed more specifically, although they are included as a service within the existing areas</p>	<p>Thanks for this comment. At this point we will not re-organize the three areas of interest. Mental health-related outcomes are covered in all three areas of interest, but, as the reviewer notes, are not separately called out.</p>
Peer Reviewer #3	Guiding Questions	<p>The questions were appropriate. Consider adding question specifically for issues related to menopause and related transition, and compounding effects of HIV (ie effects on bone health, cardiovascular health, cancer etc). In addition, the contraceptive and fertility needs of such women need to also be mentioned.</p>	<p>Thanks for this comment. At this point we will not re-organize the three areas of interest. These outcomes are covered in all three areas of interest, but, as the reviewer notes, are not separately called out.</p>
Peer Reviewer #1	Methods	<p>This section clearly and concisely described how the data was gathered and integrated, and how balance and thoroughness was ensured. It did describe engagement with Key Informants, and their role in shaping the report. Since technical briefs are explicitly not charged with judging the quality of works assessed it is very difficult to gauge whether the paucity of published articles is a peccadillo balanced by the quality of the lot, or whether it is a fatal flaw. This issue cannot be laid at the feet of the authors of the brief, but rather to the rules that are applied to this sort of document. While the authors are not charged with gauging quality they could point out challenges. For example they note that menopausal women are included in several publications, but not whether valid definitions of menopause were used in the studies cited.</p>	<p>Thank you for this comment. We have added information pertaining to this in the limitations section:</p> <p>Because we did not evaluate the results or quality of the studies that were included in the evidence map, it is difficult to know whether the paucity of studies is offset by their quality, but the overall heterogeneity of the interventions and outcomes suggests that much more research is needed.</p>
Peer Reviewer #2	Methods	<p>The methods are clearly described. It was a great idea to include a key informant group for this topic- and as they predicted the available literature on the questions posed was very limited.</p>	<p>Thanks, no reply necessary.</p>

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Peer Reviewer #2	Methods	The literature review was an enormous amount of work with a limited return. It seems that the initial search was just too broad.	Thanks, no reply necessary.
Peer Reviewer #2	Methods	It is not clear why claims data were not used or considered as a source of information. Also it seems the authors failed to consider other existing resources such as the CDC Medical Monitoring Project which has been collecting information on resources utilization in a random sample of HIV infected adults. Focusing the literature searches on studies directly focused on women may have missed more general studies from which information could be extracted (albeit without the level of detail needed).	These sources are out of the scope of the Technical Brief, but we have added language about them as a source of data in the Next Steps section: Other sources of this sort of data include claims data, the CDC Medical Monitoring Project, and large cohort studies, such as Women's interagency HIV study (WISE), the NA Accord, the SUN study, and Ryan White data (HRSA).
Peer Reviewer #2	Methods	The internet search as a means of assessing available resources was of limited value. It is difficult to know whether the services shown are actually still in existence.	We have added this language to the limitations section of the report.
Peer Reviewer #2	Methods	Also the method of comparing available resources by region and standardizing this to the general population was not helpful. If anything they should examine these resources in relation to the population of women living with HIV.	We have added the same version of the figure standardizing by the number of people with HIV in the respective state.
Peer Reviewer #2	Methods	It seems difficult to believe that local health jurisdictions cannot provide data on the numbers of women living with HIV by age and race. This information is available from County level jurisdictions in California -available on the internet with a quick search (http://publichealth.lacounty.gov/wwwfiles/ph/hae/hiv/2013annualsurveillancereport.pdf)	These reports provide information on the marginal distributions by various factors, but not on how these factors break down in older women. Surely, such information can be obtained by analyzing the raw data, but we did not ask local health jurisdictions for such analyses.
Peer Reviewer #3	Methods	Sound methodology. Addition of vignettes highlights the issues and makes it more "personal".	Thank you.
Public Reviewer #2 (Laura Cheever)	Methods	This is very strict inclusion criteria	Thank you for the comment. The inclusion criteria were indeed strict, but this is the information that the Office for Women's Health sought.

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Public Reviewer #2 (Laura Cheever)	Methods	Please clarify if these are considered separately for HIV-related person-level outcomes and non-HIV-related person-level outcomes: “Examples of person-level outcomes included clinical outcomes, such as . . .”	We have clarified this section: All patient-level and system-level outcomes were eligible, both HIV-related and not. Examples of person-level outcomes included . . .
Public Reviewer #2 (Laura Cheever)	Methods	Please clarify if the studies are weighted by the strength of evidence (study design, sample size, biases, etc.).	We have added the following sentence at the end of the Data Abstraction and Data Analysis section: Due to the nature of the project, studies were not weighted by their strength of evidence. We have also added information on evaluating risk of bias to the limitations section.
Public Reviewer #2 (Laura Cheever)	Methods	10 years seems like an arbitrary cutoff. Would like to see sensitivity analyses considering some slightly older studies as many issues, like stigma, are not new	Thank you. This is a good suggestion, but it is beyond the scope of the current project.
Public Reviewer #2 (Laura Cheever)	Methods	Please clarify if studies were included if had only some US study subjects. If interested in US studies, it would be helpful to identify the studies that included non-US populations and the percentage of study subjects that were from the US	We now clarify at the beginning of the findings section that all 37 included studies were conducted in the U.S.
Public Reviewer #2 (Laura Cheever)	Methods	The previous page refers to inclusion if the study had US participants and now the inclusion is based on US affiliation of author - please clarify which is the correct inclusion criteria. Inclusion based on US participants is preferable, as author affiliation can change over time and many authors are affiliated with multiple institutions or change institutions over time, some of which may be international, and there is no way to know which affiliation the authors selected for each publication.	We have added the following to the Limitation section: To operationalize this, we limited our search to at least one author with a U.S. affiliation (a more sensitive approach that would both limit the number of studies to be screened but not exclude potentially relevant multi-country studies that included a U.S. site). In screening, we excluded a study only if it reported that it had been done exclusively in another country. Nevertheless, this exclusion may have lead us to miss studies conducted in the U.S. by non-U.S.-affiliated researchers or researchers whose affiliation has changed over time.
Public Reviewer #2 (Laura Cheever)	Methods	Please clarify how many reviewers examined the full text eligibility and whether the reviewers trained similar to the process used for abstract screening.	We have added this information to both the methods and limitations sections.

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Public Reviewer #2 (Laura Cheever)	Methods	Please clarify if the reason for exclusion not recorded for excluded abstracts.	We have clarified in the Literature Identification and tracking section: All potentially eligible citations were retrieved and screened in full text for eligibility. We did not record reasons for exclusion at the abstract level.
Public Reviewer #2 (Laura Cheever)	Methods	A single investigator abstracting all the data leaves room for error and validity concerns	We have added a comment on this to the limitations section: The fact that screening and data extraction were done by a single person, due to limited time and resources, could have led to errors and possible improperly excluded studies. Nevertheless, we believe that the overall picture of the research is accurate.
Public Reviewer #2 (Laura Cheever)	Methods	Important to also note that the experiences of a single social worker may not be representative of experiences of other staff members in the same facility or experiences of staff members at other facilities. Therefore, extrapolation to other settings should be limited.	We have added this wording to the end of the Vignettes section of the Methods.
Public Reviewer #2 (Laura Cheever)	Methods	Please clarify if any consideration was given to the availability of public transportation in each area.	We have added this information: These states are diverse in terms of geographical location, HIV prevalence overall and among women, ² political culture, health systems, per capita income, availability of public transportation, and proportion of women with HIV who are foreign born or belong to a racial minority.
Public Reviewer #2 (Laura Cheever)	Methods	Please also refer to the Medicaid expansion status of the states.	This information has been added to the bottom of Table 6.
Public Reviewer #2 (Laura Cheever)	Methods	For the literature review, "older" was defined as 40+ years and many women over 40 have significant computing skills	We have made this change: Clearly, some older women living with HIV/AIDS are unlikely to have this sort of access to or familiarity with the Internet, but the patient navigators and social workers who work with them should.
Public Reviewer #2 (Laura Cheever)	Methods	However, patient navigators and social workers should have access to resources other than an Internet search	Thank you. You make a good point, but the intent of the search was to find information that would be available to anyone.

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Public Reviewer #3 (Vickie Lynn)	Methods	Change to: Clearly, some women living with HIV who are older are unlikely to have this sort of access to or familiarity with the Internet	We have made this change: Clearly, some older women living with HIV/AIDS are unlikely to have this sort of access to or familiarity with the Internet, but the patient navigators and social workers who work with them should.
Peer Reviewer #1	Findings	It is hard to measure the success of the findings section, particularly in regard to part A, since the guidance for reviewing states that “this section should include how the technology/intervention works, claims regarding benefits and risks, proposed use/indication, proposed settings, FDA and/or commercial status; accreditation or training issues (if applicable); information on diffusion of the technology/intervention in healthcare; whether it is commonly considered standard of care or experimental; and any important ethical, privacy, equity, and/or cost considerations.” As noted above, no easily definable intervention is ever mentioned. Rather broad problems and an amalgam of interventions, each of which might focus on a small piece of a big puzzle, are listed.	Thank you. This is a good point, but as noted earlier, this is not a standard Technical brief.
Peer Reviewer #1	Findings	In looking at the evidence map, it appears that inclusion criteria may have been too austere. Unless reviewers are willing to extrapolate or interpolate from publications that consider a wider age swath of HIV-infected women, several valuable lessons that can be learned from the extant literature may be ignored. In addition for issues such as family planning services, it is hard to justify an exclusion of studies that include women under 40 since that age group comprises the overwhelming majority of women who utilize such services.	Thank you for the comment. The inclusion criteria were indeed strict, but this is the information that the Office for Women’s Health sought. In the Next Steps section, we note that information for some outcomes may be available in studies that have enrolled broader populations.

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Peer Reviewer #1	Findings	<p>The term “engaging resources” is not ideal. “Engaging” could be an adjective or a verb. Assuming the latter, who is doing the engaging, the patient or some community group? The interventions often appear important but somewhat random. Among women with many physical, social and psychological challenges, it appears that there is no overarching prioritization (I recognize prioritization is not the charge of authors of briefs) of what would be most meaningful. Thus smoking cessation, and engaging the internet are noted, but there seems to be no attempt to prioritize what needs to be done first, or what will have the biggest bang for the buck. Perhaps that is the most important message of the findings, the need for someone or some group to start the task of organizing research to determine how to proceed (vide infra). On page 23 they discuss barriers to accessing care. I couldn’t tell in the context of the discussion whether some of those factors (e.g., sociodemographic) were barriers or associations. This also harkens back to a theme—defining terms. Are barriers self-defined by participants or is there some objective measure (e.g., what if a patient states that there are no buses in her neighborhood, when in fact there are buses)? A similar problem occurs in Area 2 (page 25) in which they evaluated the effect of insurance coverage on “outcomes.” Outcomes are only defined by the studies that were listed, such that the effect of insurance coverage on internet access is described, but not on AIDS-related deaths. Again, it would be helpful to know what the authors believe would be important to find, before listing all the anodyne works available.</p>	<p>Thank you for your comments. They are well taken, but the aim of this Technical Brief was to describe the information that exists in the recent literature for the three areas of interest, and does not involve a critique of the relative importance of interventions and/or outcomes.</p> <p>We also added a paragraph in the discussion, limitations section: We did not conduct a detailed analysis of the 37 eligible papers. For example, we did not prioritize outcomes by their importance. Antiretroviral adherence, quality of life, smoking cessation, and engaging the internet are all outcomes that were assessed, but these outcomes do not span the set of measures that is pertinent for decision and policy making. Similarly, we did not do a detailed analysis of the risk of bias or the strength of evidence of individual studies or of the entire evidence-base, because these tasks were not relevant to the goal of this project, which was to describe the literature in broad terms. We believe that formal risk of bias and strength of evidence assessments would not materially affect the interpretation of our findings or change conclusions, because of the paucity of directly relevant data.</p>

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Findings	<p>The vignettes were supposed to be illustrative of the diverse universe of affected individuals. However the first vignette was so sui generis (transgender, silicone breast injections in a hotel room, renal failure, compartment syndrome) that it's utility as a learning point is suspect. The last three vignettes are much more useful.</p> <p>I'm also not sure of the point of detailing all the services available at the Miriam Hospital; Miriam is no doubt a state of the art facility that offers services that would be the envy of almost all other institutions. If the point was to illustrate best practices, then the purpose was served. But the description occurs within a section on the general availability of resources, and the Miriam Hospital is, in that regard, an outlier, not an exemplar. Finally while a list of resources found on line, or through the various DOHs, is useful, it doesn't necessarily tell the full story. Was any attempt made to see if appointments were available at the sites that they found, or if all insurance was accepted at that site or if any subgroups were not welcome (e.g., drug addicted individuals)?</p>	<p>We have moved the first vignette to the end of the list, to highlight the relative importance of the other three.</p> <p>We have clarified that we include the Miriam program as an example of a good or "model" program: We provide a description of the clinic's operations, to give an appreciation of how patients are handled in everyday life in an exceptionally good program.</p> <p>We agree that the web survey does not tell the whole story. We have added the following to the Limitations section: Finally, the Internet search as a means of assessing available resources is of limited value, because it is difficult to know whether the services shown are still in existence and which are truly available to which patients (e.g. if appointments were available at the programs identified through these sites, if all insurance was accepted, or if any subgroups were not welcome, such as drug addicted individuals).</p>
Peer Reviewer #2	Findings	The finding that only 4% of the papers identified in the literature review were able to provide useful data highlights the challenge of the question for this technical brief. The data that were found are well organized.	Thank you.
Peer Reviewer #2	Findings	The description of the resources available at the Immunology Clinic at Miriam hospital were interesting but there was no mention of how these services are financed and supported. A key point regarding recommendations about how services should be organized is to understand how they are paid for. I suspect sites that don't have all of these services face is limited funding.	While this is a good point, we deemed it peripheral to the technical brief and did not expand on this in the discussion. We aimed to keep the discussion section as short as feasible.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	Findings	The findings regarding effective health care from a websearch are limited. The tables that summarize this information according to the size of the local population are misleading. It would have better to focus these surveys on cities or counties for which data exists on the numbers of women over the age of 40 with HIV- then the services could be examined in the context of the numbers of women living with HIV- this rate varies considerably between the 6 sites examined.	We have added such graphs normalizing by the number of HIV patients in the state.
Peer Reviewer #3	Findings	The findings are sobering, even though not unexpected. There is a paucity of information on the magnitude of the issue in the U.S., as well as the available health care resources, impact of insurance, or research related to health conditions specific to these women. Recommendations should more explicitly add the need for better quality demographic information, as well as overall burden in the U.S. of women >40 living with HIV/AIDS.	We have added this comment to the Research Needs in the Next Steps section.
Peer Reviewer #3	Findings	Another issue that might need more highlighting is the contraceptive needs of these women, as the age group studied does overlap with the reproductive age span. In addition, the issue of the child bearing desires of older women living with HIV needs consideration. There are unique contraceptive considerations among women>40 living with HIV, as well as increasing availability of fertility technologies, and these require mention, even though they may affect only a portion of such women.	We have added a comment about this aspect in the background section: Some of these women may still be of childbearing age and will have unique contraceptive and/or fertility needs. It is possible that studies on these topics may have been excluded because they did not meet other inclusion criteria.

Commentator & Affiliation	Section	Comment	Response
Public Reviewer #1 (Martina Savedra)	Findings	The methodology seems questionable. It is interesting that the Google search did not turn up any LGBTQ or women-specific HIV resources in Southern California. When conducting a simple search in Google of HIV+Women+Escondido, the San Diego LGBT Community Center appeared on the first page. When conducting a search for HIV+Women+Los Angeles, the East Los Angeles Women's Center appeared, which is a resource specific to women. Furthermore, nationally recognized Christie's Place provides HIV social services and support to women, children, and families throughout San Diego County, including Escondido. Christie s Place is found on the resource list within the link thebody.com and appears on the first page when a search of HIV+women+Southern California was conducted.	This section has been expanded to clarify and include the suggested resources: At the time of the search, these Web sites did not include any programs that focus on woman, senior citizens, or LGBTQ. Searching separately on Google for women, HIV, and specific cities or regions turns up several groups focused on women and/or the LGBT community.
Public Reviewer #2 (Laura Cheever)	Findings	Provide reasons why these articles have not yet been retrieved	All articles have now been retrieved and either included or excluded with a reason for exclusion.
Public Reviewer #2 (Laura Cheever)	Findings	When using this phrase, please indicate the number of studies to which this applies with (n=X): "Among the studies that reported information on the racial descent of participants, the median proportion of African American, Latino/Hispanic . . ."	We have added this information: Among the 28 studies that reported information on the racial descent of participants,
Public Reviewer #2 (Laura Cheever)	Findings	Please clarify if is one or two studies: "Only one or two studies reported on the proportion of women who were illegal immigrants, experienced violence, or . . ."	We have clarified this information: Only one or two studies reported on the proportion of women who were undocumented immigrants (1 study), experienced violence (2 studies), or had a history of incarceration (1 study).

Commentator & Affiliation	Section	Comment	Response
Public Reviewer #2 (Laura Cheever)	Findings	Please clarify if this list of sociodemographic factors was determined by the investigators a priori or developed based on what was reported in each study. (TABLE 1)	We have clarified that these factors were established in the Key Informant discussions: person- or system-level outcomes or examined modifiers of said relationship as established in the Key Informant discussions
Public Reviewer #2 (Laura Cheever)	Findings	Please clarify if these outcomes were in addition to HIV care outcomes or examined without HIV care outcomes: “Almost all of the barriers studied involved engaging or retention in HIV care, though one each evaluated cancer screening, accessing program services, and using the internet.”	We have clarified: Almost all of the barriers studied involved engaging or retention in HIV care, though one each exclusively evaluated outcomes not related to HIV, including cancer screening, accessing program services, and using the internet
Public Reviewer #2 (Laura Cheever)	Findings	A risk of bias analysis would strengthen the argument that these are not causal studies. If not going to do this secondary analysis, be more specific about the methods in the papers that excludes them from being causal analyses. “of insurance on outcomes, despite having done no formal risk of bias analysis for them”	We have added more specific information about what keeps these papers from being casual: These studies were not designed to estimate the causal effect of insurance (relying on simple regression analyses instead of causally explicit methods, such as propensity scores, instrumental variables, or marginal structural modeling), did not use causally explicit analyses, and each considered and controlled for different variables.
Public Reviewer #2 (Laura Cheever)	Findings	"Mental health factors" (plural) are mentioned, yet only history of depression is explicitly listed. Please clarify if other mental health factors were studied. “CD4 counts, and viral load), and mental health factors (history of depression)”	We have expanded this sentence to clarify: and mental health factors (including a history of depression, anxiety, or psychosis).
Public Reviewer #2 (Laura Cheever)	Findings	Please clarify if the vignettes are presented verbatim from the social worker or if the text is the interpretation/summary from the investigators. In qualitative studies, this can influence how the results are interpreted.	We have clarified this: The following vignettes are summarized from the descriptions given to us by the Miriam Hospital social worker. They emphasize the need for case management and individualized care and give an indication of the range of needs that various older women have and the barriers they face in accessing care.

Commentator & Affiliation	Section	Comment	Response
Public Reviewer #2 (Laura Cheever)	Findings	This conclusion does not follow from the vignette, which explicitly states "...is on treatment with good disease control" "M.W.'s battles with depression, chronic disease, stigma, and lack of social support have had major adverse impact on her well-being and adherence to HIV"	We have clarified that while she now has the disease under control, this has not always been the case.
Public Reviewer #2 (Laura Cheever)	Findings	As stated later in the vignette, substance abuse issues are not her only barrier to care. As stated, this places all the burden on the substance abuse issues, which is an oversimplification of intersecting barriers. (CW): <i>"regularly misses clinic appointments and does not regularly take her HIV medications, because she faces substance abuse issues."</i>	We have added to that sentence to clarify that there are multiple reasons for her lack of adherence: She regularly misses clinic appointments and does not regularly take her HIV medications, because she faces substance abuse, mental health, family, and social issues.
Public Reviewer #2 (Laura Cheever)	Findings	In addition to HIV providers who may refer clients to specialists for other health and social issues: "combination of word of mouth referrals (e.g., from those who make the HIV diagnosis) and various community outreach programs."	We have added the reviewer's language: It is not clear how most patients are linked to HIV care resources, but it is likely that it comes through a combination of word of mouth referrals from HIV providers, who may refer clients to specialists for other health and social issues, and various community outreach programs.
Public Reviewer #2 (Laura Cheever)	Findings	These 3 types of people do not fall into the same category of "web-savvy" persons, as they would all use different search terms and have different baseline knowledge of resources which would impact the results of a web search. They are not a homogenous group. As conducted, this section most closely represents the experiences of an HIV-infected woman who is not in HIV care and does not have access to a provider referral network.	We have added a comment about the fact that this person does not have access to a provider referral network.
Public Reviewer #2 (Laura Cheever)	Findings	A discussion of locator.aids.gov would be beneficial, as it is an important tool to assist people living with HIV locate care resources and readily accessible.	We have expanded our mention of locator.aids.gov: In addition, we show what resources are available using the tools at locator.aids.gov, which provides a graphical interface for locating resources throughout the U.S..

Source: <https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=2328>

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Commentator & Affiliation	Section	Comment	Response
Public Reviewer #2 (Laura Cheever)	Findings	The investigators could have reached out to the health departments for some of these data points	We have addressed this limitation in the Limitations section: Finally, the Internet search as a means of assessing available resources is of limited value, because it is difficult to know whether the services shown are still in existence and which are truly available to which patients (e.g. if appointments were available at the programs identified through these sites, if all insurance was accepted, or if any subgroups were not welcome, such as drug addicted individuals).
Public Reviewer #2 (Laura Cheever)	Findings	A person's "infection route" cannot be known definitively. Instead, this variable should be labeled "transmission risk category". (Table 7)	We have adopted this wording.
Public Reviewer #2 (Laura Cheever)	Findings	The use of general population values as the denominator for these rate calculations is inappropriate. Given the focus on women living with HIV, a rate per 1000 women living with HIV or per 1000 persons living with HIV would be a better representation of resource density, especially given the diverse geographic areas included and their varying levels of HIV prevalence. As currently calculated, density does not reflect the availability of resources specifically for women living with HIV, which is the focus of this report. (Table 8)	We have added such graphs normalizing by the number of HIV patients in the state.
Public Reviewer #2 (Laura Cheever)	Findings	These figures are uninformative due to the inconsistent axes that are difficult to interpret. Density per 1000 persons living with HIV would be a better outcome for this analysis (with the exception of HIV testing resources, which apply to the entire population). (Figure 3)	We have added such graphs normalizing by the number of HIV patients in the state.
Public Reviewer #2 (Laura Cheever)	Findings	For completeness, such a description should be included for an example resource in each state. The emphasis on Miriam hospital here and in the vignettes and for no other facilities introduces the potential for bias.	Thank you. This is a good suggestion, but it is beyond the scope of the current project.

Commentator & Affiliation	Section	Comment	Response
Public Reviewer #2 (Laura Cheever)	Findings	This description outlines the clinic protocols and not necessarily the experiences of clients accessing services in the clinic. Both sides should be presented for a more complete assessment of the client experience.	Thank you. This is a good suggestion, but it is beyond the scope of the current project.
Public Reviewer #3 (Vickie Lynn)	Findings	Page 17: Age of contraction is difficult to access – age of diagnosis and length of time diagnosed might be more valid	We have adopted this wording throughout.
Public Reviewer #3 (Vickie Lynn)	Findings	As we are well aware public insurance keeps people stuck – when they try to better themselves they immediately loss their public health insurance, which leaves them with limited options.	Thank you.
Public Reviewer #3 (Vickie Lynn)	Findings	Page 39: “person’s case manager, using a language interpreter”	We have made this change.
Public Reviewer #3 (Vickie Lynn)	Findings	Page 39: because, existing resources within and outside the clinic are rarely integrated.	We have made this change.
Peer Reviewer #2	Summary and Implications	The amount of evidence that was available from the search performed was very limited. This makes it difficult to come up with a very strong summary and Implications section. The authors do identify many important challenges faced by this population of poor underinsured women with complex health needs.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Public Reviewer #3 (Vickie Lynn)	Summary and Implications	As researchers, it is critical that we use "preferred language" when discussing the health conditions of the populations throughout society and often repeated by professionals and lay workers, thus further stigmatizing the people we are trying to help. The use of inappropriate language in relation to HIV and AIDS issues may result in continued stigma and discrimination towards people living with HIV and may hinder prevention, treatment, and educational efforts. We all play a critical role in translating research to practice in a culturally sensitive and respectful manner.	We have made a number of language changes, suggested by this and other reviewers, to ameliorate this problem.
Public Reviewer #2 (Laura Cheever)	Summary and Implications	Please provide a citation. "Women with adequate insurance coverage may paradoxically access a narrower range of resources, because they are not as widely exposed to community-based resources and other peer and social support services."	We have noted that this came out of the KI calls: As was noted in our conversations with the Key Informants, women with adequate insurance coverage may paradoxically
Public Reviewer #2 (Laura Cheever)	Summary and Implications	As currently worded, this implies that there were zero resources of any kind in some areas. However, there was limited availability of specific types of resources. (bottom of P 41)	We have adopted the reviewer's wording: Our Web-based survey yielded a sizeable number of testing, housing, medical and mental health, and social support resources in the largest cities, and limited availability of specific types of resources in the median and smallest cities in the six states.
Public Reviewer #2 (Laura Cheever)	Summary and Implications	Public transportation can also be incredibly time consuming	We have added this language: Traveling even a few miles in a big city can be difficult and time-consuming especially when one does not have private means of transportation

Source: <https://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=2328>
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Commentator & Affiliation	Section	Comment	Response
Public Reviewer #2 (Laura Cheever)	Summary and Implications	This analysis did not assess how difficult it was to access information (time spent searching, number of search engines examined, number of pages visited to obtain resource information, etc), but rather the availability of that information. This would also be an ideal place to discuss locator.aids.gov as a valuable, comprehensive, up-to-date resource.	We have added this information in the Summary and Limitations sections.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Next Steps	<p>1. The authors explicitly acknowledge that it is not their charge to prioritize research. Their first suggestion about how to move forward is via re-analysis of existing data sets. The problem is they never discussed those sets, or whether they contained data that could answer their research questions if they were to be reanalyzed. Similarly when they suggest moving to broader data sets (e.g., men and women) to see if some questions could be addressed though those, we do still left not know which data sets contain the requisite information.</p> <p>2. In regard to encouraging consortia along the lines of ACTG or WIHS, that would be a pricey approach indeed, as opposed to asking already existing consortia to consider adding the necessary data points to allow them to help address the questions of greatest moment. That in turn raises what I believe is the most critical issue. Before considering how to answer “questions” there is a need for prioritization and clarification, and potentially going beyond the three conceptual areas introduced as objectives. Unless those areas are first refined and prioritized, any search for data will be quixotic.</p> <p>3. Point four on page 44 touches on this, providing a very brief outline of prioritization techniques. These are useful even though they are offered in only précis form. However, they assume that the questions are agreed upon and now merely need to be prioritized. I think the questions as formulated are still too vague to serve as useful Sherpas for the exploration of this subject.</p>	<p>Thank you for these comments. They are well taken, but as noted earlier the goal of this project was to inform the Office for Women’s Health’s research prioritization exercise by describing what research has been done.</p> <p>1. As the reviewer notes, the next steps are described at a high level of abstraction, as is appropriate when there are no specific prioritized questions. Evaluating the 853 studies that were excluded only because they did not report results in women over the age of 40, while a good idea, was outside the scope of this project.</p> <p>2. We have added a comment about having these consortia expand their scope: It is also possible that these existing consortia could be convinced to expand their scope to include the research questions addressed in this Technical Brief.</p> <p>3. Thank you.</p>

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	Next Steps	The next steps section was limited. The suggestion to mine existing data sources with meta-analyses was a good one. Some consideration of studies using claims data might be included. Also the restriction of the literature review to studies focused on women may have missed some larger studies addressing the use of HIV care services that were not broken down by age and sex. More specific suggestions of how to get the needed data would strengthen this report.	We have added claims data to the next steps section: Other sources of this sort of data include claims data, the CDC Medical Monitoring Project, and large cohort studies, such as Women's interagency HIV study (WISE), the NA Accord, the SUN study, and Ryan White data (HRSA).
Peer Reviewer #3	Next Steps	Suggestions for future research are thoughtfully presented, to which I would add need for more information on U.S. burden of disease among this group and any socioeconomic and ethnic disparities.	We have added this research need: 1. There is a need for better quality demographic information, as well as overall burden in the U.S. of women over the age of 40 living with HIV/AIDS.
Public Reviewer #2 (Laura Cheever)	Next Steps	Alternatively, this report could be used to advocate for the inclusion of these types of questions in already-existing consortia	We have added a comment about having these consortia expand their scope: It is also possible that these existing consortia could be convinced to expand their scope to include the research questions addressed in this Technical Brief..
Public Reviewer #2 (Laura Cheever)	Next Steps	This discussion could be supplemented with a search of NIH Reporter to see if any currently or recently-funded studies address these populations and are either still in progress or have not yet been published. Searches of conference abstracts could also provide a sense of the future direction of the field.	Thank you for this comment, but this is beyond the scope of the current project.
Peer Reviewer #1	Clarity and Usability	As stated in the general comments section above, after reading this document one is left feeling that the only thing that is clear is how unclear the science is at the moment. The authors mounted a quite credible literature search, drew up an intelligible evidence map, but were hamstrung by the paucity of relevant publications, and in my estimation by objectives that were overly diffuse. Until the objectives are refined, the task of prioritizing questions and creating pathways to answers will be hobbled.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	Clarity and Usability	The information that was summarized was presented in a clear and organized manner. The tables of studies include data that will be helpful to a user of this report. I would have liked to see more specific suggestions for future research needs for this population.	Thank you.
Peer Reviewer #3	Clarity and Usability	The report is very clear, well structured and well organized, with the main points clearly presented, and very thoughtful discussion and suggestion of next steps. The conclusions can be used to inform the setting of future research priorities, to which one might consider adding the need for better surveillance data from CDC or other agencies in the U.S. Family planning and fertility intentions and related services need to also be addressed.	Thank you.

References:

1. CDC. Diagnoses of HIV Infection in the United States and Dependent Areas, 2014. HIV Surveillance Report; 2014.
2. HIV and AIDS in the United States by Geographic Distribution. Atlanta, GA: Centers for Disease Control and Prevention. <http://www.cdc.gov/hiv/statistics/basics/geographicdistribution.html>. Accessed on September 7, 2015.