

# Using Community Health Workers to Address Barriers to Participation and Retention in Diabetes Prevention Program: A Concept Paper

Journal of Primary Care & Community Health  
Volume 13: 1–9  
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DOI: 10.1177/21501319221134563  
journals.sagepub.com/home/jpc



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## Abstract

**Objective:** The PreventionLink of Southern Maryland is a 5-year project to eliminate barriers to participation and retention in the National Diabetes Prevention Program (DPP) lifestyle change program to prevent or delay the onset of type 2 diabetes in adults with prediabetes. This is the study to identify the obstacles to participation and retention in the DPP lifestyle change program among high burden populations and learn how CHWs have reduced the identified barriers to participation and retention for high burden populations. **Methods:** We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) to conduct this literature review. We have used the Scopus and PubMed, including all types of studies and peer-reviewed documents published in English between 2010 and 2020. **Results:** From 131 identified articles, 18 articles were selected for qualitative synthesis. The reviewed literature documented following as main barriers to participate in a DPP lifestyle change program: time, cost, lack of transportation, cost of transportation, commute distance, technology access, access to facilities and community programs, caregiver responsibilities, lack of health literacy and awareness, and language. CHWs can address these barriers to participation and retention, they were involved in educating and supporting roles; they worked as bridges between healthcare providers and participants and as intervention team members. **Conclusions:** Diabetes prevention program participants with social determinant risk factors who most need CHW services are unlikely to have financial resources to pay for CHW services out-of-pocket. Hence, the public and private health plans that pay for their prediabetes care should consider paying for these CHW services and there is a need to trust more to CHW and have them as a “community health teams” member.

## Keywords

community health workers, volunteers, diabetes, pre-diabetes, prevention, lifestyle, literature review

Dates received: 31 August 2022; revised: 3 October 2022; accepted: 6 October 2022.

## Introduction

Diabetes is a major public health problem in the US, with a prevalence rate of 10.5% and over 34.2 million people with diabetes in 2018.<sup>1</sup> Approximately 88 million Americans have prediabetes, it is predicted that as many as 1 in 5 Americans could develop diabetes by 2025,<sup>2,3</sup> lifestyle change interventions are key components to reduce the risk of developing type 2 diabetes. The Diabetes Prevention Program (DPP) demonstrated that people engaged in a structured lifestyle change program reduced their chance of developing type 2 diabetes by 16 percentage points per year.<sup>2,4</sup> Congress authorized the CDC to establish the

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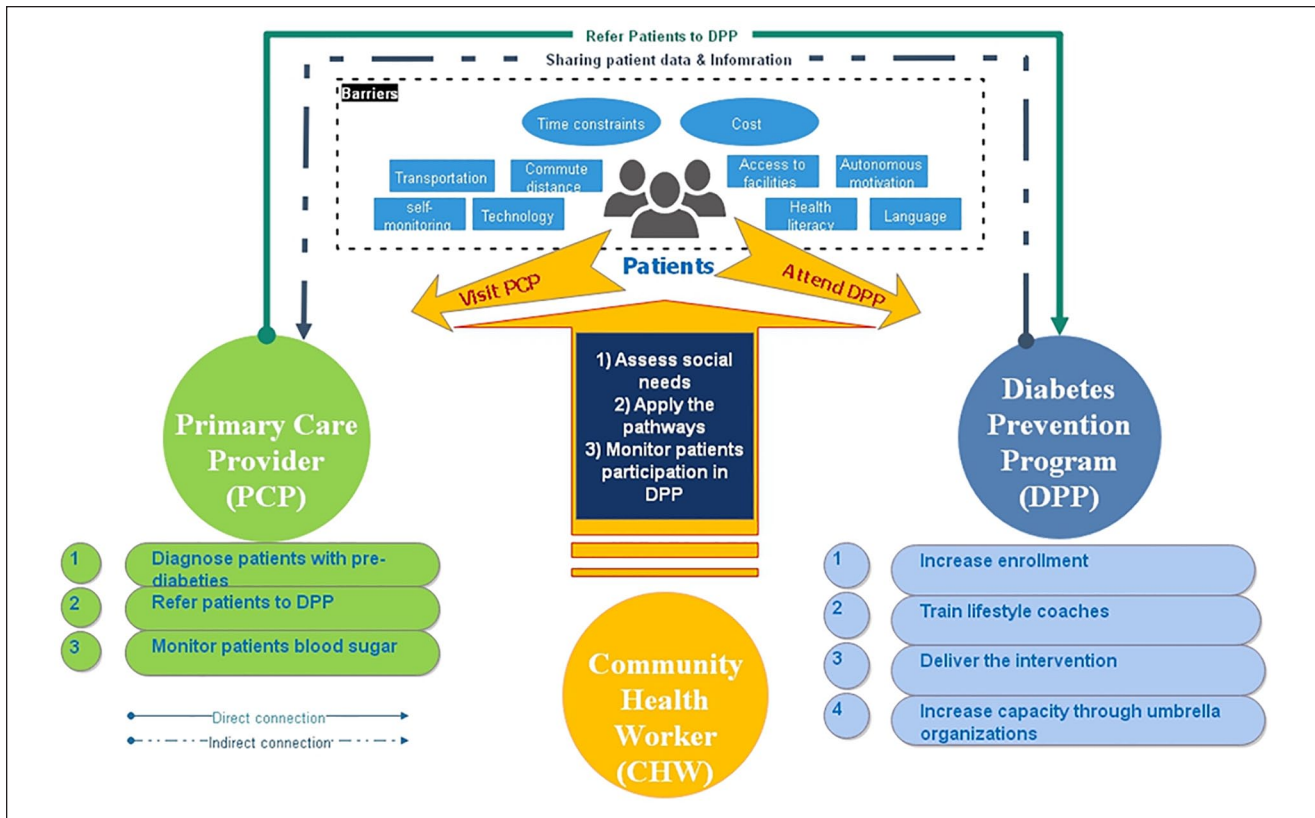
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**Figure 1.** The study conceptual framework.

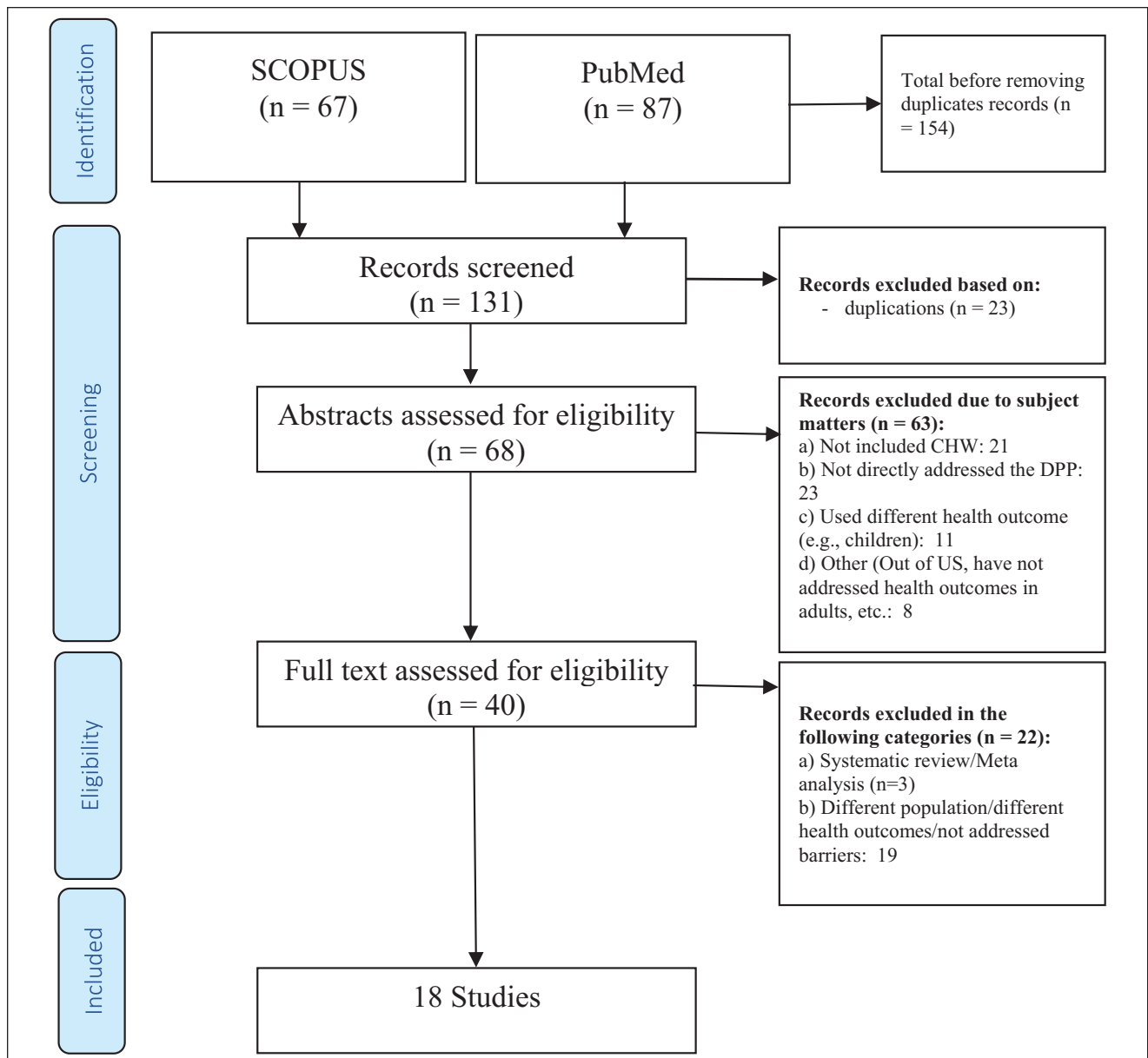
National Diabetes Prevention Program (National DPP) in 2010.<sup>4-9</sup> The program is group-based, facilitated by a trained lifestyle coach, and uses a CDC-approved curriculum. Despite evidence that a structured lifestyle intervention can delay or prevent the development of type 2 diabetes,<sup>10-12</sup> some organizations have had difficulty enrolling sufficient numbers of participants to sustain program services long-term.<sup>13,14</sup> Identifying the barriers and facilitators to enrollment are crucial steps to improving recruitment and retention in CDC-recognized lifestyle change programs for type 2 diabetes prevention. The present paper seeks to: (1) examine the literature to understand how barriers or facilitators influence recruitment and retention (or lack thereof) in a lifestyle change program for type 2 diabetes prevention, and (2) identify Community Health Worker (CHW) interventions that can effectively address these barriers.

### Prince George's County Health Department (PGCHD) Approach

PreventionLink of Southern Maryland is a 5-year project funded by the CDC and led by the PGCHD. One of the strategies is "to explore and test innovative ways to eliminate barriers to participation and retention in CDC-recognized lifestyle change programs for type 2 diabetes prevention

among high burden populations." PreventionLink will implement a CHW intervention to eliminate barriers to participation and retention in the National DPP lifestyle change program. CHWs use the Evidence-Based *Pathways Community Coordination* model<sup>15</sup> and Accountable Health Communities (AHC) Model<sup>16</sup> to document the patients' assessed needs and refer them to the community resources that respond to those needs. These pathways address problems with (1) transportation, (2) health literacy, (3) financial assistance, (4) social service support, (5) medication self-management, (6) self-monitoring, and (7) access to facilities.

Figure 1 illustrates how the PreventionLink CHW intervention will work. Primary care providers in participating practices will refer patients with prediabetes to a CDC-recognized organization. Referred patients will be screened for unmet social needs using a screening tool adapted from the Accountable Health Communities Health-Related Social Needs Screening Tool,<sup>17</sup> the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE),<sup>18</sup> and the Health Literacy screener tool.<sup>19</sup> Patients with unmet social needs<sup>20</sup> will be referred to a CHW. The CHW will perform detailed social determinants of health assessment to determine what the patients' needs are and then provide patients with the



**Figure 2.** PRISMA chart of the study.

appropriate pathway services to address barriers to their participation in a CDC-recognized lifestyle change program for type 2 diabetes prevention and to meet Maryland's unique Total Cost of Care Model.<sup>21</sup>

## Literature Review

### Part A: Review of Barriers to Enrollment and Retention

Research method: To conduct this review, we followed the steps suggested for Preferred Reporting Items for Systematic

Reviews and Meta-Analyses (PRISMA).<sup>21</sup> The PRISMA Flowchart includes 4 main steps including identification, screening, eligibility, and including articles for analysis (see Figure 2). We conducted 2 literature reviews to assess the feasibility of using CHWs to effectively address the barriers to participation and retention in the National DPP lifestyle change program among high burden populations. The objective of the first review is to identify barriers to participation and retention. The second review assesses the evidence that CHWs can effectively reduce the identified barriers to participation and retention for high burden populations.

**Table 1.** Reported Barriers to Diabetes Prevention Program Participant Enrollment and Retention Based on the Reviewed Publications: 2010 to 2020.

Article	Barriers identified
Albright and Gregg, <sup>2</sup> Gary-Webb et al, <sup>22</sup> Griauzde et al, <sup>23</sup> and Venditti et al <sup>24</sup>	Time
Gary-Webb et al, <sup>22</sup> Griauzde et al, <sup>23</sup> Reddy et al, <sup>25</sup> and Thomas et al <sup>26</sup>	Cost
Gary-Webb et al, <sup>22</sup> Dyer et al, <sup>27</sup> and Jiang et al <sup>28</sup>	Transportation and cost of transportation
Reddy et al <sup>25</sup> and Dyer et al <sup>27</sup>	Commute distance
Reddy et al <sup>25</sup>	Self-monitoring
Griauzde et al, <sup>23</sup> Dyer et al, <sup>27</sup> and Bian et al <sup>29</sup>	Technology access
Albright and Gregg, <sup>2</sup> Reddy et al, <sup>25</sup> and Thomas et al <sup>26</sup>	Access to facilities and community programs
Griauzde et al, <sup>23</sup> Venditti et al, <sup>24</sup> and Thomas et al <sup>26</sup>	Autonomous motivation
Thomas et al <sup>26</sup> and Jiang et al <sup>28</sup>	Caregiver responsibilities
Albright and Gregg <sup>2</sup>	Health literacy and awareness
Nhim et al <sup>30</sup>	Language

Source: Study findings based on literature review (2010-March 2020).

**Barriers and retention review criteria.** The review included many types of studies (including but not limited to case-control, cross-sectional, and cohort studies), and all types of peer-reviewed documents (eg, original research articles, reviews, and reports) published in English between 2010 and 2020. The following were excluded from the review: articles published in languages other than English, articles that addressed type 2 diabetes prevention programs not utilized in the United States, non-peer-reviewed and systematic review articles, and articles focusing on interventions not related to diabetes prevention.

We conducted an electronic search using the databases Scopus and PubMed through March 28, 2020. We also conducted a citation search of selected articles to identify additional relevant studies. We obtained full-text reviews for studies that were initially selected and assessed whether the article met the eligibility criteria listed above. Our findings are discussed in the next section.

**Effectiveness of CHWs review criteria.** Using the inclusion and exclusion criteria described above, we conducted another search including “CHW” OR “Community Health Workers.” We identified 154 articles from the initial electronic search and 4 articles from the manual citation search. We excluded 114 articles by screening the titles and abstracts using the study eligibility criteria. After removing duplicates, 40 articles were selected for full-text review of eligibility. Finally, we selected 18 articles with the most relevant studies regarding CHW roles in addressing barriers for patients in diabetes prevention programs.

## Results

### Barriers reported in similar studies

Multiple barriers to participation and retention in diabetes prevention programs were identified in the thirteen (13) articles (see Table 1) that were reviewed, as follows:

**Time constraints:** The time constraints of potential program participants were identified as a common barrier in multiple research articles.<sup>22,25</sup> Setting aside time to attend the 16 weekly sessions was a barrier for some participants, particularly those with low socioeconomic status.<sup>2</sup> Time constraints were also a barrier when program sessions were extended beyond the scheduled time frame.<sup>22</sup> Among diabetes prevention programs that utilized technology to engage participants, lengthy and time-consuming apps resulted in loss of interest and participant disengagement.<sup>23</sup> Last, participants’ time management and planning was identified as a barrier to program adherence and participation.<sup>24</sup>

**Cost:** The out-of-pocket costs participants incur for various program components, for example, recreational center fees so that they can engage in exercise, are a barrier to participant engagement and retention.<sup>22,23</sup> The cost barrier was even more significant for uninsured individuals who were unable to pay the entire program cost out-of-pocket.<sup>26</sup> To lessen these financial burdens, some programs have offered scholarships for participants who commit to complete a minimum of 75% of the sessions.<sup>25</sup>

**Transportation:** Lack of transportation and transportation costs to attend weekly program sessions emerged as a barrier in multiple studies.<sup>22,27</sup> Although in some studies, short-term retention was not affected by transportation, long-time retention was difficult to achieve and resulted in participant attrition.<sup>28</sup> Some program delivery organizations have addressed the transportation barrier by giving participants limited value transit passes<sup>22</sup>; however, this approach is of limited utility in rural areas that generally lack public transportation options.

**Commuting time:** In multiple studies, the time involved in traveling to facilities to attend in-person sessions was identified as a barrier by participants commuting from rural areas in multiple studies.<sup>25,27</sup> To address this barrier, participation outside of the class through small groups was encouraged.<sup>27</sup> Alternative options included programs delivered

online or through distance learning where participants could attend without needing to travel.<sup>27,31</sup>

*Self-monitoring:* Self-monitoring of food intake is well-established as a crucial behavioral change strategy for weight loss. Lower household income and low educational attainment were significantly associated with less frequent dietary self-monitoring among diabetes prevention program participants.<sup>24</sup>

*Technology access:* Some organizations have used technology to increase participants' access to the program via online service delivery with the premise that this mode of service delivery may allow a larger number of persons to participate, may increase geographic access to this service, and may reduce the per participant cost, and thus improve the cost effectiveness of the intervention.<sup>32</sup> However, despite the finding that online programs have proven to be as effective as in-person models, some participants were challenged by the online technology.<sup>29</sup> Limited computer literacy or access, especially among older populations, has been a cause for online participant dissatisfaction.<sup>27,31</sup> In addition, participants lacking internet access or smart devices are unable to participate meaningfully in online programs.<sup>23</sup> Additionally, some older participants prefer to have in-person services.<sup>33</sup> Furthermore, for an online program to operate efficiently, it needs the full-time support of professional online coaches; not all programs have such resources.<sup>32</sup>

Accessibility of digital technology allows users to initiate interventions effortlessly but also allows users to disengage easily, so online programs need to define elements that make their programs successful.<sup>34,35</sup>

*Access to facilities and community programs:* Access to community-based exercise facilities are another identified barrier.<sup>2</sup> Multiple program participants experienced challenges accessing the necessary space and equipment to engage in exercise.<sup>25</sup> Lack of support from community programs and exercise facilities such as fitness centers may negatively impact participant retention.<sup>26</sup>

*Lack of motivation:* Participants who lacked motivation to change their lifestyle tended to either not enroll or to not complete the program.<sup>24</sup> Conversely, participants who were highly motivated to make the necessary changes tended to remain engaged and complete the program.<sup>23</sup>

*Caregiver responsibilities:* Participants who were caregivers reported that caregiving responsibilities negatively impacted their ability to enroll and remain in a diabetes prevention program.<sup>26</sup> Although, in some studies, short-term retention was not affected by care-giving responsibilities, long-term retention was difficult to achieve.<sup>28</sup>

*Health literacy:* Among individuals with multiple type 2 diabetes risk factors, studies have found that an overall lack of awareness may further increase risk. For these patients, brief education or consulting about how they can

influence their risk may help to reduce progression to higher levels of risk.<sup>2</sup>

*Language:* Language difficulties have been identified as barriers to diabetes prevention program enrollment and retention among vulnerable and disadvantaged groups.<sup>30</sup> While the information is conveyed to participants, there are barriers to a successful delivery. Some online programs are available only in English, thus limiting access to non-English speakers.<sup>36</sup> To address the language barrier, some organizations have opted to use native speaker facilitators with experience in community outreach to deliver the program.<sup>22</sup>

## Part B: The Role of CHWs in Facilitating Retention in Diabetes Prevention Programs

As summarized in Table 2, CHWs have been involved in diabetes prevention programs to support patients. Among the selected articles and referenced citations reviewed, the main roles and responsibilities of CHWs are summarized in 3 main categories: (1) educating and supporting roles of CHWs, (2) CHWs as bridges between healthcare providers and participant, and (3) CHWs roles as intervention team members.

*Educating and supporting roles of CHWs.* CHWs are engaged in patient care and support, outreach, and patient education.<sup>46</sup> They play a major role in training and counseling participants.<sup>8,42,47</sup> They mitigate the barrier of time constraints by facilitating small groups of participants who met on a flexible schedule.<sup>27,46</sup> They also provide practical support, such as offering transportation to diabetes prevention program sessions, so that participants are able to attend to the program to reach program goals.<sup>41</sup> Additionally, they maintain regular contact with participants and provide them with ongoing support and information.<sup>48</sup> In one program, the CHWs employed a computer-based mapping system to locate healthcare resources for patients.<sup>43</sup> In another program, the CHWs engaged participants in teach-backs, role playing, and group discussions designed to improve the participants' health literacy.<sup>45</sup> Therefore, CHWs play a role in educating and counseling participants.<sup>8,47</sup>

CHWs assist non-native English-speaking participants to understand their culture and to overcome language barriers for them.<sup>41,44,45</sup> In addition, evidence has shown that CHWs have great potential to reduce costs and increase accessibility to lifestyle behavioral change interventions and provide a cost-effective alternative to professional healthcare providers.<sup>38,47</sup> In the Healthy Living Partnerships to Prevent Diabetes (HELP PD), CHWs delivered a cost-effective intervention by reducing direct medical and non-medical program costs.<sup>39</sup> Huang et al<sup>49</sup> used an incremental cost effectiveness ratio method, and concluded that CHW intervention was highly cost-effective.

**Table 2.** CHW Roles in Addressing Diabetes Prevention Program Recruitment and Retention Barriers.

Article	Barriers	CHW role/intervention to address the barriers
Ruggiero et al <sup>37</sup>	Time	Providing participants with the option to meet in small CHW-facilitated groups with flexible scheduling
Katula et al, <sup>38</sup> Lawlor et al, <sup>39</sup> and Perez et al <sup>40</sup>	Cost	Reducing direct cost of the program; for example, in some CHW models, the direct cost has been as low as one-third of the original DPP intervention (\$850 vs \$2631). It may be due to using more-costly medical professionals to deliver lifestyle intervention or delivering group-based services in comparison with individual-based service.
Wagner et al <sup>41</sup>	Lack of transportation	Providing transportation
Lorig et al, <sup>42</sup> Van der Wees et al, <sup>43</sup> and Islam et al <sup>44</sup>	Self-monitoring	- Providing self-monitoring training. - Lifestyle strategies for glycemic control including physical activity, prevention of diabetes complications, healthy food, and diabetes care. - Glucose self-monitoring training
Kim et al <sup>45</sup>	Autonomous motivation	Motivational counseling
Kim et al <sup>45</sup>	Health literacy	Using a literacy-enhancing approach that addresses the strong need to enhance essential health literacy skills
Wagner et al, <sup>41</sup> Islam et al, <sup>44</sup> and Kim et al <sup>45</sup>	Language	A CHW who speaks the native language, helps a non-English speaker to understand their culture and to overcome language barriers for them.

Source: Study findings based on Literature Review (2010-March 2020).

*CHWs as bridges between healthcare providers and participants.* CHWs play other supportive roles in diabetes prevention programs, including serving as liaisons between participants and their medical providers and following up with participants to ensure they adhere to their care plan including accessing needed services,<sup>50</sup> and providing instrumental support to healthcare professionals in the delivery of care and educational programs.<sup>37</sup> They can assist participants with low health literacy by clarifying healthcare providers' instructions so that participants are able to follow the instructions.<sup>51</sup>

*CHWs roles as intervention team members.* CHWs participate in data collection such as recording of family attendance in program activities.<sup>52</sup> As a team member, CHWs improve participants knowledge and behavior regarding diabetes<sup>53</sup> self-care practice and glucose self-monitoring, diet, and physical activities.<sup>46</sup>

## Discussion and Conclusion

PreventionLink offers a viable approach to address barriers to enrollment and retention in diabetes prevention programs. Evidence shows that CHWs can help program participants overcome most of the barriers to enrollment and retention. Although technology challenges and caregiving responsibilities were identified as barriers to participant retention, no studies presented ways in which CHWs can help mitigate these barriers. Nonetheless, it is quite plausible for CHWs to facilitate participants' access to online

diabetes prevention programs by training them on how to use the technology. CHWs can also help program participants obtain child care,<sup>54</sup> adult daycare, and home health aide services. They have been shown to be an effective bridge between providers and community-based services.<sup>50,55</sup> CHWs can serve as agents for program participants, helping to make the most of their interactions with their primary care providers and their diabetes prevention programs.

A major challenge for providing any support services is how to sustain the services financially. The second is AccessHealth, which employs CHWs to provide several services. PGCHD contracts with PGHA and AccessHealth to provide these services as a part of PreventionLink. However, the ability to bill for CHW services is crucial to sustain this needed support. Diabetes prevention program participants with social determinant risk factors who most need CHW services are unlikely to have financial resources to pay for CHW services out-of-pocket. Hence, the public and private health plans that pay for their prediabetes care should consider paying for these CHW services.

Under the Medicare Diabetes Prevention Program (MDPP) Expanded Model, CMS reimburses MDPP suppliers for enrolled Medicare beneficiaries, based on a pay-for-performance model linked to attendance and weight loss goals in New Mexico.<sup>56</sup> Creating a sustainable statewide model for CHW's reimbursement needs more collaboration from local and statewide policymakers to defining type and qualifications for reimbursement, and sustainable funding and mechanisms to reimburse CHWs.<sup>57,58</sup>

States may develop policies and programs to “adopt a statewide CHW training curriculum” and “develop statewide certification/licensing process for CHWs”<sup>56</sup> to facilitate a sustainable statewide model or shifting value-based reimbursement models similar to other health professionals.<sup>59</sup>

The Centers for Medicare and Medicaid Services (CMS) reimbursement for CHW services is not unprecedented. CMS currently pays for CHW services under the Medicaid program. CMS allows states to pay for preventative care services recommended by a physician provided by a CHW, including coordinating care, addressing health literacy, supporting home-based self-management, and providing health education and promotion services. Typically, these services are offered to dually eligible beneficiaries who are high utilizers and children with special healthcare needs, such as those with asthma. PreventionLink is evaluating this strategy of using CHWs to address the barriers to participation and retention in diabetes prevention programs. If it proves to be cost effective, then CMS should consider adding payment for CHW services to the MDDP Expanded Model. CHWs have great potential to save more money by providing cost-effective services<sup>38,47</sup> to patients and communities. Their awareness of the community needs and their similarity with participants in culture and language make them powerful agents for promoting community health, this is a great investment with a significant return.<sup>60</sup> However, there is a general understanding lack of full capacity of CHWs in promoting the health of the communities. It is a 2-sided barrier at health system and professional providers and CHW (by themselves). There is a need to “trust” more in CHW-capacity at the health system and professional provider by helping CHWs to build their collaboration and integration<sup>58</sup> it is also crucial for CHWs to develop their strengths to join the “community health teams” and work as a “crucial connection between the team and the community; they can also play a vital role in building community capacity and promoting patient empowerment.”<sup>61</sup>

### Acknowledgments

The research was supported through cooperative agreement NU58DP006626-01-00 (Prince George’s County Health Department) from the U.S. Department of Health and Human Services (DHHS, Centers for Disease Control and Prevention). Dr. Ernest L. Carter, MD, PhD, the Health Officer, Prince George’s County, Maryland is the Principal Investigator. Lori Werrell, MPH, MCHES is the Co-Principal Investigator. Rigorous evaluation will be conducted by a team headed by Darrell J. Gaskin, PhD, the William C. and Nancy F. Richardson Professor in Health Policy and Director of the Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health. The Hopkins team, consisting of Darrell J. Gaskin, PhD; Hossein Zare, PhD; Roland J. Thorpe, Jr., PhD; Michelle Spencer, MS; and Laurie Thomas, PhD, an independent health services research consultant with expertise in qualitative methods. The PGHCD Evaluation team consists of Donna Perkins, MPH and Christina Gray, MS.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The research was supported through grants #:1 NU58DP006626-01-00 (Prince George’s County Health Department) from the U.S. Department of Health and Human Services (DHHS, Centers for Disease Control and Prevention). Dr. Ernest Carter, MD, PhD, the Acting Health Officer, Prince George’s County, Maryland is the Principal Investigator.

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