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Promoting Community Co-Ownership in Research Dissemination: The Healthy Engaged Lifestyle to Prevent Stroke (HELPS) Study

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ABSTRACT:

Background: Despite its importance, dissemination of community research to participants is often lacking. This paper describes the dissemination activities of the Healthy Engaged Lifestyle to Prevent Stroke (HELPS) study, which partnered with local African American communities to reduce stroke risk.

Methods: Using a Community-Centered Dissemination Toolkit, the HELPS team designed, implemented, and evaluated several methods for academic and community dissemination. This culminated in a Community Sharing Forum to share HELPS study results with participants and their family and friends.

Results: Within the Community Sharing Forum, participants shared they found value in learning how to reduce stroke risk and sharing that information with their community. They also reported a desire to share this information beyond the study's conclusion.

Conclusion: Dissemination is essential to sustainable community partnership and promoting trust through true co-ownership of the entire research process. Community-based dissemination strengthens engagement by reinforcing meaning for participants and providing valuable feedback for ongoing community health activities.

KEYWORDS:

Community health partnerships, Community health research, Health disparities, Health promotion, Cardiovascular Diseases

Background

Community-based participatory research (CBPR) is a methodology that promotes collaboration and co-ownership of the research process between academic and community partners.[1] This partnership is centered throughout all stages of the CBPR process from design to dissemination. Literature recommends planning for community dissemination from the onset of study activities and ensuring that participants are involved throughout the research process.[2-4] Dissemination serves to strengthen and maintain community relationships in research,[5] which can reduce mistrust in research and promote future engagement in research activities.[6,7] Further, researchers have an ethical imperative to disseminate research results to fully satisfy the principle of respect for participants.[8]

Despite its recognized importance, dissemination of results back to research participants rarely occurs. While nearly all CBPR researchers report *intending* to share results with their participants at the start of their research, fewer than two-thirds engage with the community at large, and less than half actually share their results specifically with participants.[5] This is further complicated by the lack of widely recommended models for CBPR dissemination to guide such implementation,[5] although use of a toolkit may provide information to consider for various audience needs and contexts. It is important to start planning for dissemination in the study's earliest stages, identifying diverse audiences, format and engagement objectives and activities. This proactive approach helps ensure that research findings translate into meaningful impact in the community [9].

The Healthy Engaged Lifestyle to Prevent Stroke (HELPS) study[10, 11] was a CBPR project that took place between March 2021 and May 2023 to engage African American communities within the Twin Cities around stroke prevention and awareness. Activities were approved by the University of Minnesota's Institutional Review Board. The study team included academic and community members: two co-principal investigators (one academic, one Community Health Strategist), one academic liaison from the University of Minnesota's Program for Health Disparities Research (PHDR), two members from the Urban Research and Outreach-Engagement Center in Minneapolis, three African American

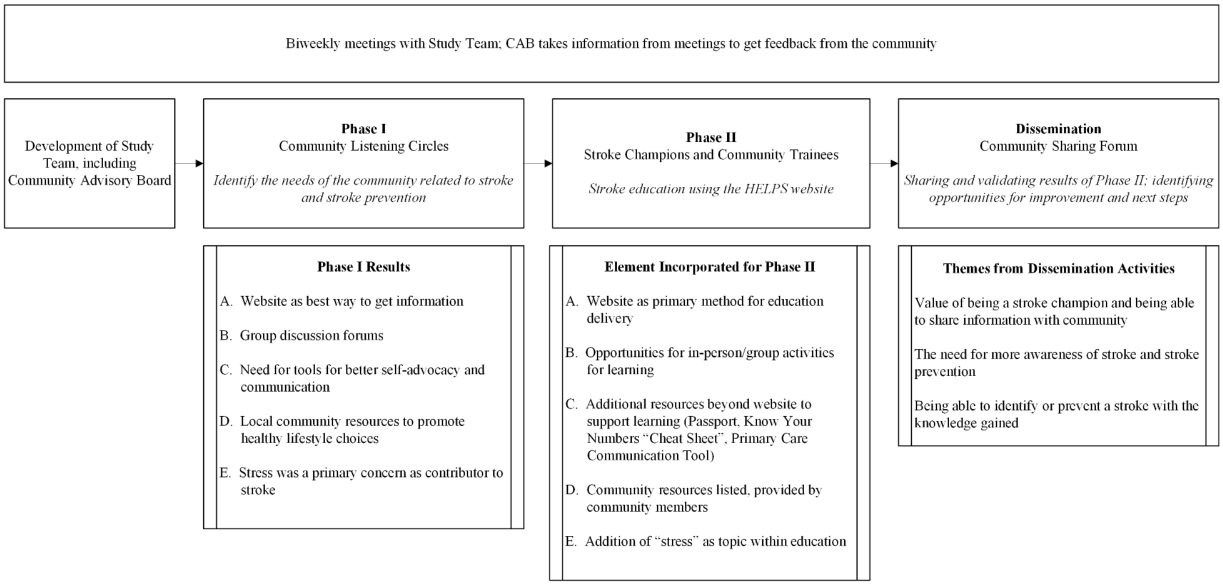
Community Health Workers (CHWs), two Doctor of Nursing Practice (DNP) Adult/Gerontological Clinical Nurse Specialist students, and one undergraduate nursing student. A community advisory board (CAB) was formed at the beginning of HELPS study activities. The CAB consisted of our community partners and the CHWs, who had additional responsibilities of taking items from biweekly meetings back to the community for feedback. This pivotal role served as a bridge between the HELPS team and research participants, enabling the study team to provide informative and educational materials that were culturally tailored and responsive to community needs.

The HELPS study[10,11] consisted of two phases. In Phase I, Community Listening Circle (CLC) focus groups explored existing participant knowledge and perceptions about stroke and stroke risk.[10] In Phase II, selected participants were educated on stroke, stroke risk factors, and stroke prevention through education modules, becoming HELPS "Stroke Champions." The Stroke Champions were asked to re-teach the information they learned to two other community members (Community Trainees).[11]

In the first phase of the HELPS study,[10] 54 African American participants attended one of seven CLCs to share existing knowledge and beliefs surrounding stroke, stroke risk factors, community barriers and facilitators to healthy behaviors, and factors that may influence participation and engagement in future study activities. Participants were highly engaged in these conversations and showed genuine interest in health problems present in the community. Additionally, they readily identified mistrust and historical research as a significant barrier, noting that "researchers do research on us and then leave without letting us know results".[10] Participants also shared ways that researchers could leverage community strengths and resources to address barriers, build trust, and engage community participation in the next steps of the HELPS study.

The importance of the CLCs cannot be overestimated as they provided key information that informed subsequent study activities, ensured that activities were being delivered in a way that was desirable and tailored to participants, and most importantly, promoted a foundation of trust and engagement needed throughout the duration of the HELPS study. Participants were asked specifically about methods that they found most beneficial for communication about health-related information, including HELPS study activities and results. This was an iterative and flexible process throughout the HELPS study to ensure that all participants had the opportunity to receive HELPS study education and result information. CHWs, as members of our CAB, served as translators and provided connections between team members and participants throughout the research and dissemination process. Please see Figure 1 which illustrates the process by which each phase of the study informed the steps from inception of the HELPS study to dissemination.

Figure 1. Methodological Process of the HELPS Study



Methods

The HELPS study[10,11] applied the University of Minnesota PHDR and CTSI's Community-Centered Dissemination Toolkit[12] during their dissemination activities. The steps described within the Community-Centered Dissemination Toolkit provided a comprehensive approach to HELPS study dissemination activities, including: (1) gather a dissemination team, (2) define a dissemination goal, (3) develop an action plan, (4), identify the resources, and (5) evaluate the impact of the dissemination plan.

Other researchers may find that this toolkit can be adapted to their own studies as a potential strategy to promote engagement, collaboration, and co-ownership between academic and community partners.

Step 1: Gather the Dissemination Team

Academic and community partners played pivotal and unique roles throughout the design, implementation, and review of study results; thus, each member of the HELPS study team was included as part of the dissemination process. Team members met biweekly to discuss study progress and opportunities for dissemination. Community members, in particular, were essential in establishing and strengthening connections with community organizations, events, and media outlets. Our community advisory board served to articulate the perceptions, preferences, and priorities throughout the research and dissemination process. The study team established that conflict and opinion differences between academics and community members may arise, and it is important to address those as equal partners in the CBPR process. The trust that was established as a result of this ground rule was evident during meetings.

Step 2: Define a Dissemination Goal

There were four main goals identified in our dissemination program:

(1) To raise awareness and promote engagement in the Twin Cities African American communities on the topics of stroke and stroke prevention.

(2) To facilitate conversations about stroke and stroke risk, and counter barriers with strengths and resources identified by the community members.

(3) To promote trust, encourage co-ownership of information, and build trusting relationships between community members and academic research partners.

(4) To validate HELPS study results and learnings with participants and community members and refine them where necessary.

Step 3: Develop an Action Plan

Ensuring that our dissemination action plan met the needs and preferences identified by the community was essential to our study's success. While survey data indicated that participants preferred to receive health information in a variety of methods, delivering information required a personal presence and connection beyond education delivery alone. In addition to regularly scheduled meetings and formal study education sessions, HELPS team members were frequently in touch with Stroke Champions by phone, email, or meeting in person to ensure that questions were answered and that participants felt supported throughout the study process. Additionally, the team attended several community events based on the recommendation of a Community Health Strategist and participants to reach others beyond just the HELPS study team member and participant social networks. These community events provided an important opportunity to not only raise awareness about the study, stroke prevention, and health information, but also provided opportunities for direct feedback and collaboration throughout the study process. This mutual exchange of ideas and information provided an important opportunity to improve on processes in real time and enhance the success of the academic-community partnership and study activities.

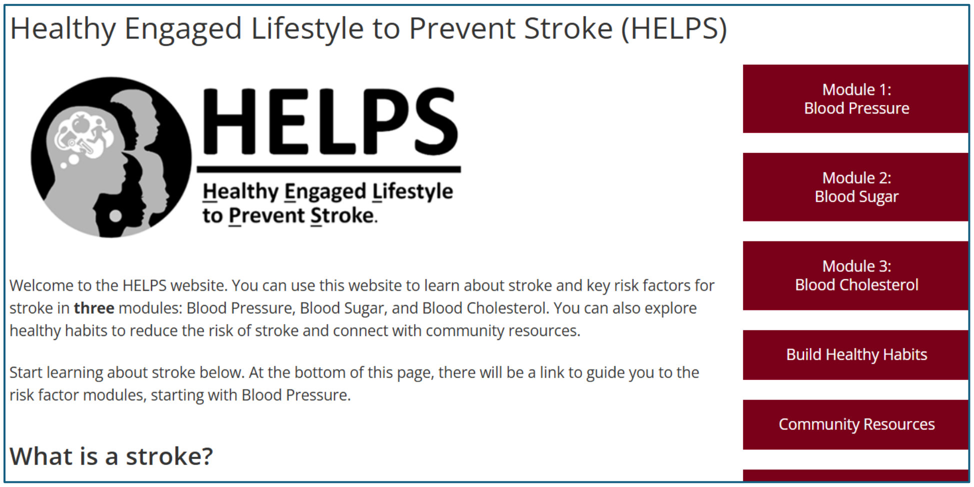
Step 4: Identify Resources

Resources utilized throughout the HELPS study were identified during community-academic study team meetings, where community members provided suggestions on events and spaces in which to more broadly engage the community. To meet these requests, DNP students on the study team developed several print and virtual resources, including the following, which can be seen in Figures 2-7:

- The HELPS study website[13]: A comprehensive resource for Stroke Champions and Community Trainees describing the top three risk factors for stroke, including each risk factor's relationship to stroke, how it is measured, and ways to reduce risk. The website also included recommended lifestyle modifications and community resources. Content for the website was derived from the American Heart Association[14-27] and American Stroke Association.[28-32]

- A HELPS “passport” booklet: This pocket-sized guide contained a condensed summary of the information above, as well as spaces for users to track their own measurements, medications, and questions.
- A “Know Your Numbers” “cheat sheet”: This reference tool provided key values for each risk factor as well as the ability for the user to track each longitudinally. This information was identical to that presented in the passport booklet but in single sheet form.
- A primary care communication tool: This goal setting tool was developed to help users prepare for their appointments, organize health information, communicate with clinicians and prioritize goals between visits.

Figure 2. HELPS Study Home Page



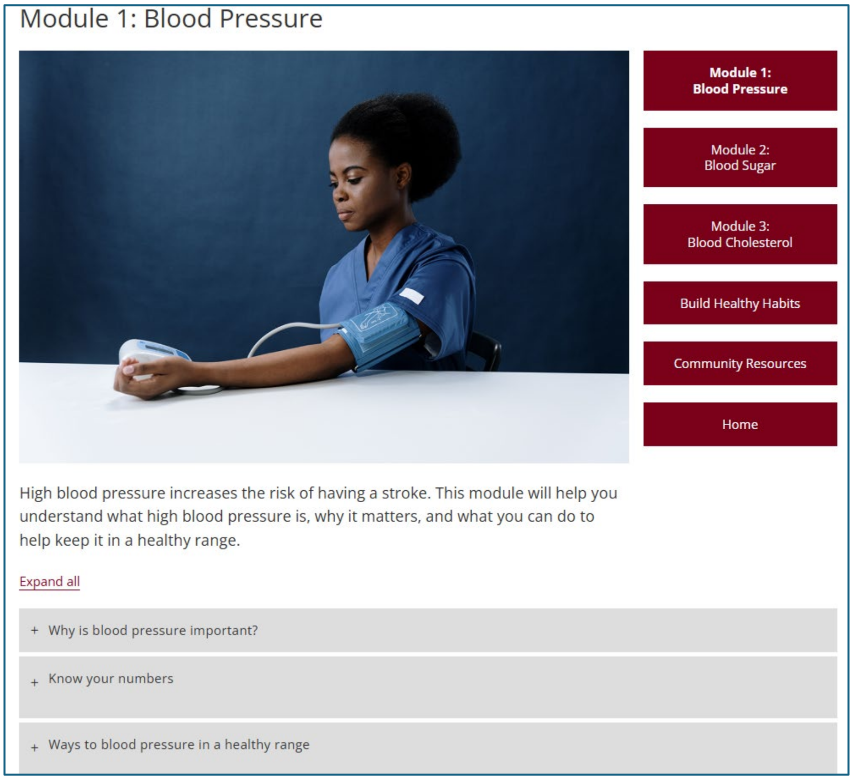
Healthy Engaged Lifestyle to Prevent Stroke (HELPS)

Welcome to the HELPS website. You can use this website to learn about stroke and key risk factors for stroke in **three** modules: Blood Pressure, Blood Sugar, and Blood Cholesterol. You can also explore healthy habits to reduce the risk of stroke and connect with community resources.

Start learning about stroke below. At the bottom of this page, there will be a link to guide you to the risk factor modules, starting with Blood Pressure.

What is a stroke?

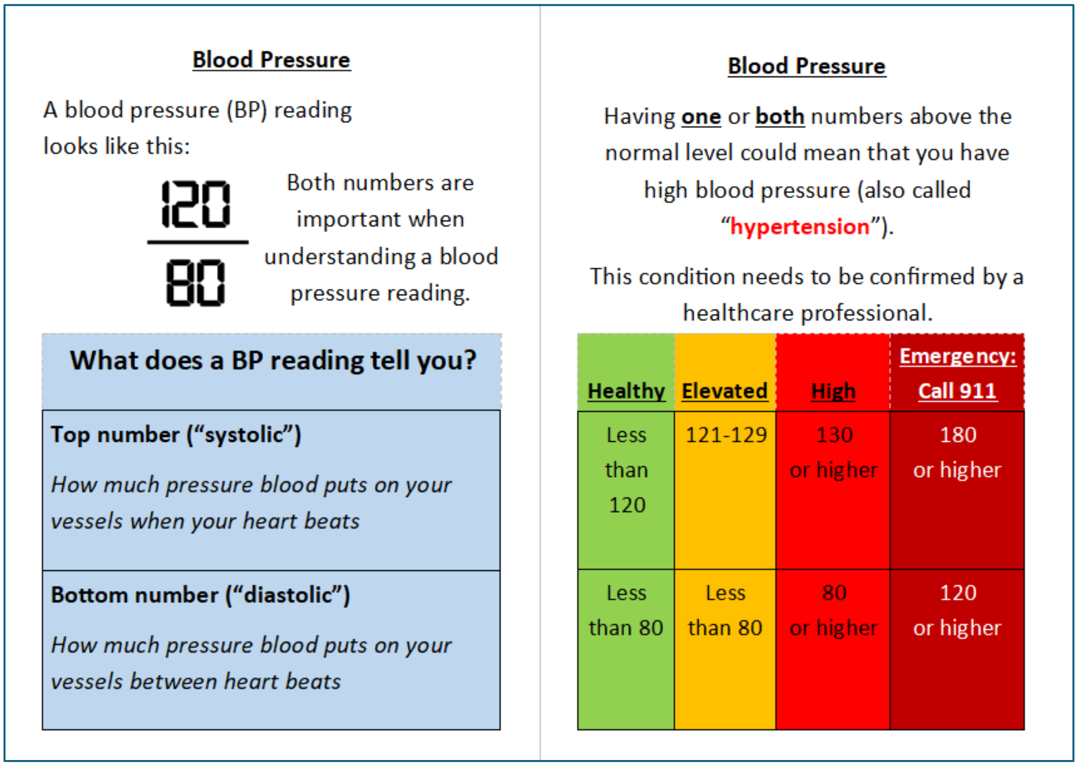
Figure 3. Sample module within HELPS Study website. Note that content can be expanded for visitors to explore topics within each area.



Module 1: Blood Pressure

High blood pressure increases the risk of having a stroke. This module will help you understand what high blood pressure is, why it matters, and what you can do to help keep it in a healthy range.

Figure 4. Sample Page from Health Passport Booklet



Blood Pressure

A blood pressure (BP) reading looks like this:

120
80

Both numbers are important when understanding a blood pressure reading.

What does a BP reading tell you?

Top number ("systolic")

How much pressure blood puts on your vessels when your heart beats

Bottom number ("diastolic")

How much pressure blood puts on your vessels between heart beats

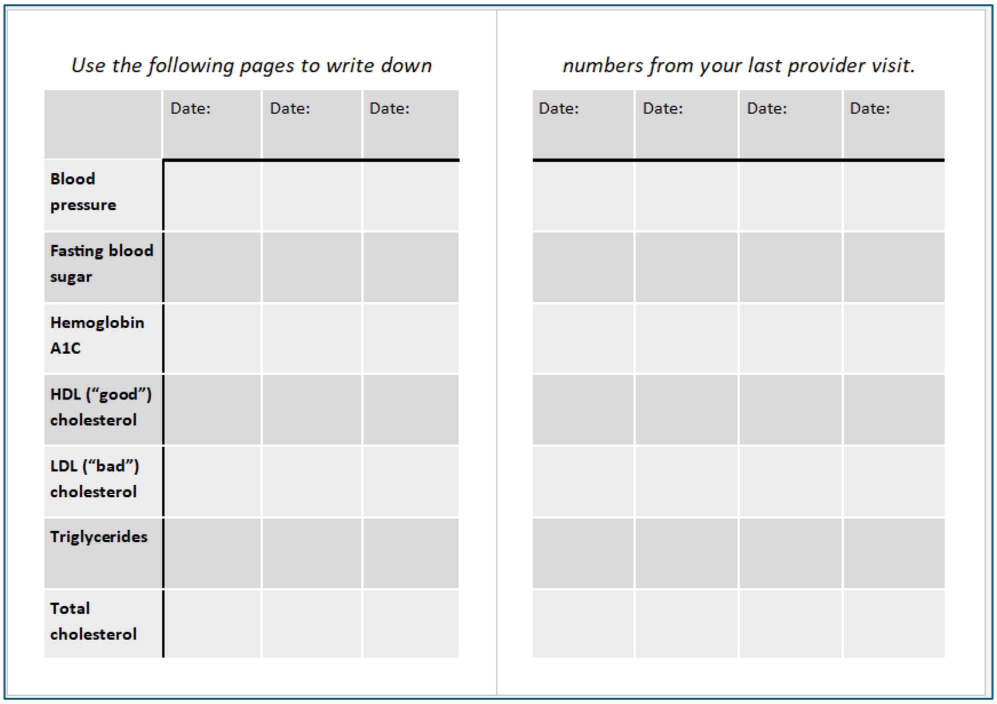
Blood Pressure

Having **one** or **both** numbers above the normal level could mean that you have high blood pressure (also called "**hypertension**").

This condition needs to be confirmed by a healthcare professional.

Healthy	**Elevated**	**High**	**Emergency: Call 911**
Less than 120	121-129	130 or higher	180 or higher
Less than 80	Less than 80	80 or higher	120 or higher

Figure 5. Sample of Tracking Log from Health Passport Booklet



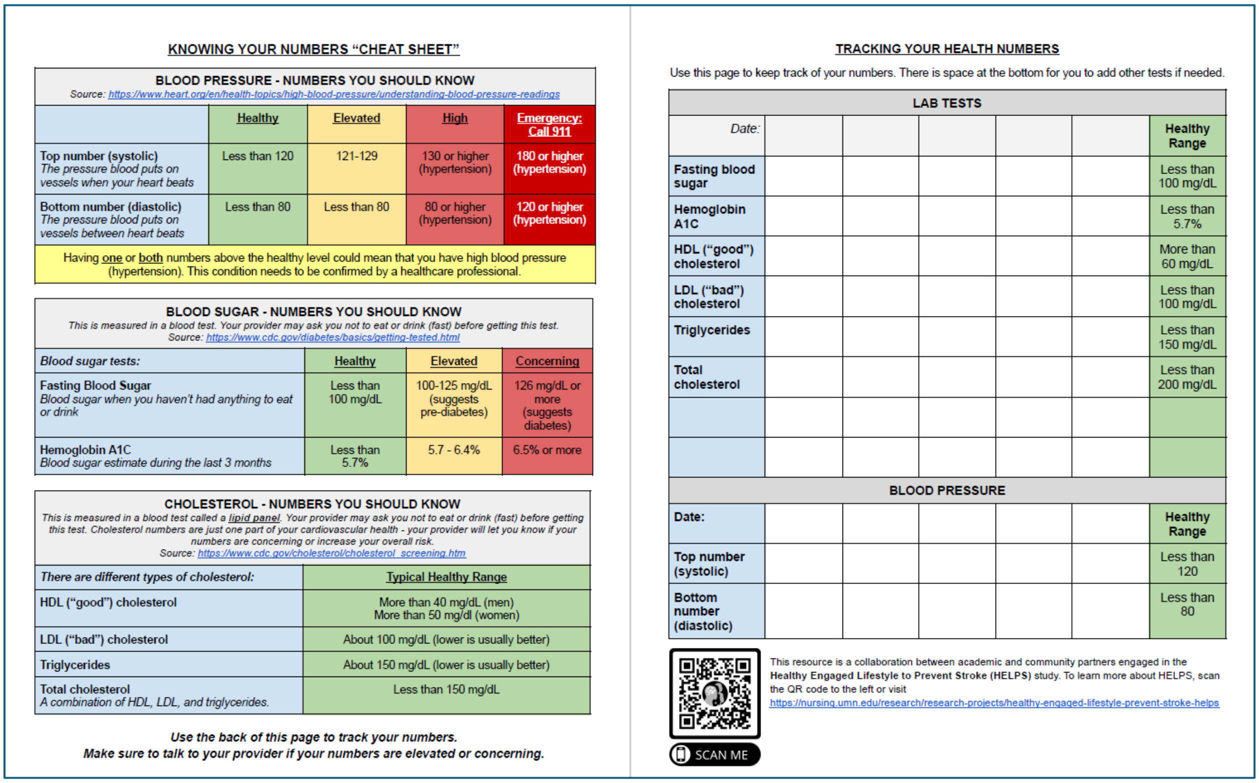
Use the following pages to write down

	Date:	Date:	Date:
Blood pressure			
Fasting blood sugar			
Hemoglobin A1C			
HDL (“good”) cholesterol			
LDL (“bad”) cholesterol			
Triglycerides			
Total cholesterol			

numbers from your last provider visit.

Date:	Date:	Date:	Date:

Figure 6. Knowing Your Numbers “Cheat Sheet”



KNOWING YOUR NUMBERS "CHEAT SHEET"

BLOOD PRESSURE - NUMBERS YOU SHOULD KNOW
Source: https://www.heart.org/en/health-topics/high-blood-pressure/understanding-blood-pressure-readings

	Healthy	Elevated	High	Emergency: Call 911
Top number (systolic) *The pressure blood puts on vessels when your heart beats*	Less than 120	121-129	130 or higher (hypertension)	180 or higher (hypertension)
Bottom number (diastolic) *The pressure blood puts on vessels between heart beats*	Less than 80	Less than 80	80 or higher (hypertension)	120 or higher (hypertension)
Having one or both numbers above the healthy level could mean that you have high blood pressure (hypertension). This condition needs to be confirmed by a healthcare professional.				

BLOOD SUGAR - NUMBERS YOU SHOULD KNOW
This is measured in a blood test. Your provider may ask you not to eat or drink (fast) before getting this test.
Source: https://www.cdc.gov/diabetes/basics/getting-tested.html

Blood sugar tests:	Healthy	Elevated	Concerning
Fasting Blood Sugar *Blood sugar when you haven't had anything to eat or drink*	Less than 100 mg/dL	100-125 mg/dL (suggests pre-diabetes)	126 mg/dL or more (suggests diabetes)
Hemoglobin A1C *Blood sugar estimate during the last 3 months*	Less than 5.7%	5.7 - 6.4%	6.5% or more

CHOLESTEROL - NUMBERS YOU SHOULD KNOW
This is measured in a blood test called a lipid panel. Your provider may ask you not to eat or drink (fast) before getting this test. Cholesterol numbers are just one part of your cardiovascular health - your provider will let you know if your numbers are concerning or increase your overall risk.
Source: https://www.cdc.gov/cholesterol/cholesterol_screening.htm

There are different types of cholesterol:	Typical Healthy Range
HDL ("good") cholesterol	More than 40 mg/dL (men) More than 50 mg/dl (women)
LDL ("bad") cholesterol	About 100 mg/dL (lower is usually better)
Triglycerides	About 150 mg/dL (lower is usually better)
Total cholesterol *A combination of HDL, LDL, and triglycerides.*	Less than 150 mg/dL

Use the back of this page to track your numbers.
Make sure to talk to your provider if your numbers are elevated or concerning.

TRACKING YOUR HEALTH NUMBERS

Use this page to keep track of your numbers. There is space at the bottom for you to add other tests if needed.

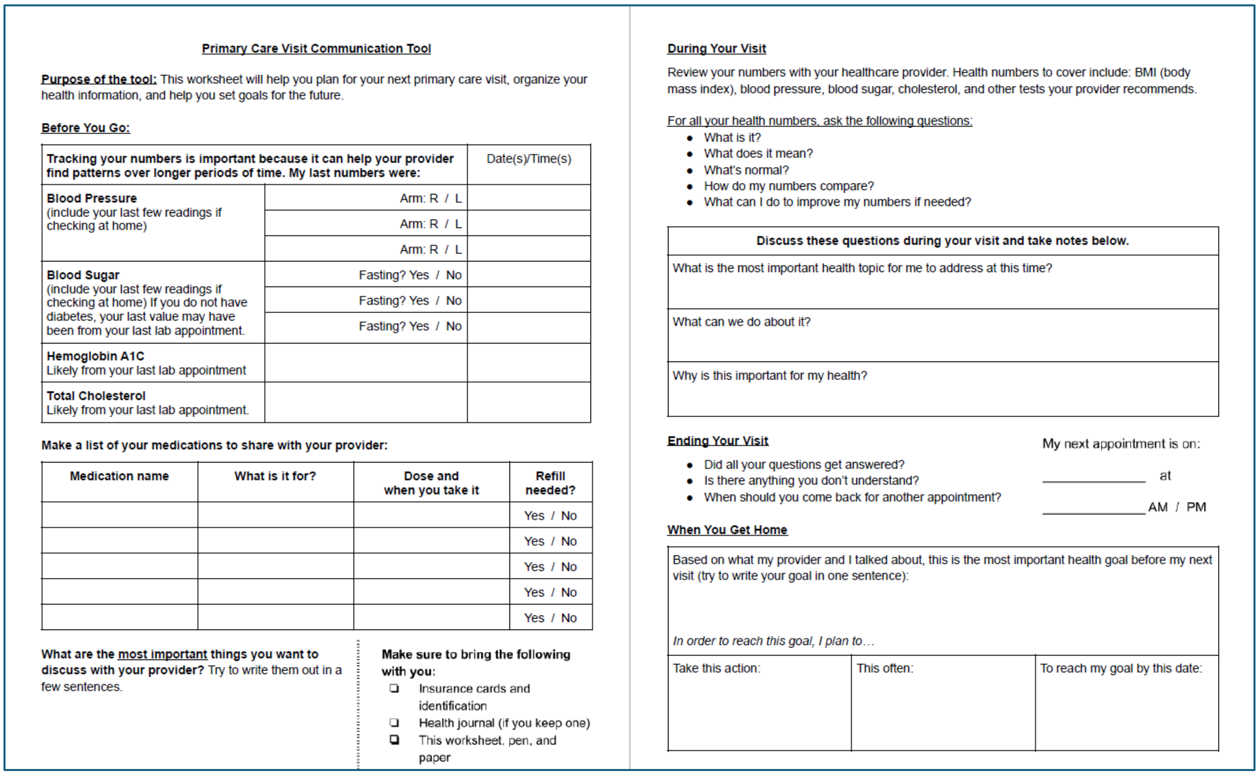
LAB TESTS						
Date:						**Healthy Range**
Fasting blood sugar						Less than 100 mg/dL
Hemoglobin A1C						Less than 5.7%
HDL ("good") cholesterol						More than 60 mg/dL
LDL ("bad") cholesterol						Less than 100 mg/dL
Triglycerides						Less than 150 mg/dL
Total cholesterol						Less than 200 mg/dL

BLOOD PRESSURE						
Date:						**Healthy Range**
Top number (systolic)						Less than 120
Bottom number (diastolic)						Less than 80

SCAN ME

This resource is a collaboration between academic and community partners engaged in the **Healthy Engaged Lifestyle to Prevent Stroke (HELPS)** study. To learn more about HELPS, scan the QR code to the left or visit https://nursing.umn.edu/research/research-projects/healthy-engaged-lifestyle-prevent-stroke-helps

Figure 7. Primary Care Visit Communication Tool



Primary Care Visit Communication Tool

Purpose of the tool: This worksheet will help you plan for your next primary care visit, organize your health information, and help you set goals for the future.

Before You Go:

Tracking your numbers is important because it can help your provider find patterns over longer periods of time. My last numbers were:		Date(s)/Time(s)
Blood Pressure (include your last few readings if checking at home)	Arm: R / L	
	Arm: R / L	
	Arm: R / L	
Blood Sugar (include your last few readings if checking at home) If you do not have diabetes, your last value may have been from your last lab appointment.	Fasting? Yes / No	
	Fasting? Yes / No	
	Fasting? Yes / No	
Hemoglobin A1C Likely from your last lab appointment		
Total Cholesterol Likely from your last lab appointment.		

Make a list of your medications to share with your provider:

Medication name	What is it for?	Dose and when you take it	Refill needed?
			Yes / No
			Yes / No
			Yes / No
			Yes / No
			Yes / No

What are the most important things you want to discuss with your provider? Try to write them out in a few sentences.

Make sure to bring the following with you:
- ☐ Insurance cards and identification
- ☐ Health journal (if you keep one)
- ☐ This worksheet, pen, and paper

During Your Visit

Review your numbers with your healthcare provider. Health numbers to cover include: BMI (body mass index), blood pressure, blood sugar, cholesterol, and other tests your provider recommends.

For all your health numbers, ask the following questions:
- What is it?
- What does it mean?
- What's normal?
- How do my numbers compare?
- What can I do to improve my numbers if needed?

Discuss these questions during your visit and take notes below.
What is the most important health topic for me to address at this time?
What can we do about it?
Why is this important for my health?

Ending Your Visit
- Did all your questions get answered?
- Is there anything you don't understand?
- When should you come back for another appointment?

My next appointment is on:

______________ at

______________ AM / PM

When You Get Home

Based on what my provider and I talked about, this is the most important health goal before my next visit (try to write your goal in one sentence):

In order to reach this goal, I plan to…

Take this action:	This often:	To reach my goal by this date:

While HELPS study education was based on the website that was developed, participants and community members reported the greatest value from the physical "passport" booklets. These became a primary method to distribute key health information and promote engagement with educational materials. Community members often reported that they used the passport booklet to share information with other community members, friends and relatives. They further reported that sharing this information led to identifying stroke signs and symptoms in at least one scenario. In another scenario, a participant used the booklet to recognize a high blood glucose level and asked the primary care physician for a hemoglobin A1C test rather than fasting blood glucose. Community members requested that additional booklets be disseminated in high traffic public areas such as grocery stores, places of worship, and pharmacies. Passports and print resources were included in folders and distributed at study and community events. Resource folders and the passport contained quick response (QR) codes and links to the HELPS study website, where users could peruse additional information on each health-related topic and share this information with others.

After developing the website and the passports, distribution and engagement beyond immediate HELPS study participants depended on attending several community-based health events, including a North Minneapolis Community Day (Urban Research and Outreach-Engagement Outreach Center), several South Minneapolis health fairs (Center for Changing Lives), and an event that celebrated African American men in their advocacy for organ transplant. Additionally, the Principal Investigator (PI) of the HELPS study team was interviewed on KMOJ radio, a station that aims to "[provide] communities of color with information and education through the vehicle of mass communication".[33] Finally, there was a presentation surrounding stroke and stroke prevention at Northside Urban Coalition, a group of community advocates addressing physical, cultural, social, and economic needs to empower the community.[34]

Following the conclusion of HELPS Phase II, all participants and their friends and families were invited to attend a Community Sharing Forum to share HELPS Phase I study results, ensure mutual understanding, and review the HELPS study process to identify opportunities for improvement with future CBPR activities. Participants were provided with sticky notes and were invited to answer four prompts: “What does being a Stroke Champion mean to you?”, “What can make the Stroke Champion program better?”, “What were the positives you got from this project?”, and “What other questions or comments do you have?”. The information collected from these sticky notes served as additional data for the next step of the study.

Results

Step 5: Evaluate the Impact of the Dissemination Plan

The HELPS study website remains active as part of the University of Minnesota School of Nursing’s website. As of March 10, 2025, a total of 2575 visits were noted. Additionally, 200 copies of the passports and other print resources (cheat sheet and primary care visit communication tool) were printed and distributed as part of the initial HELPS study activities; requests for these resources continue beyond the study’s conclusion. Of the dissemination methods utilized, the passports appear to be one of the most popular tools, potentially because they were easily accessible, pocket sized, containing succinct and useful information that served as a way to share information with other community members. Perhaps more notable than the numbers of distributed resources were the richness of the conversation surrounding HELPS study results at our Community Sharing Forum. Of the 12 Stroke Champions, 10 attended, and several brought their Community Trainees. Beyond sharing and validating study results, the Community Sharing Forum was an opportunity for participants to share what they found valuable and what could be improved. Please see Table 1 for summary of the community members responses during the Community Sharing Forum.

Lessons Learned

While dissemination to research participants is often noted as an important final step in the CBPR process, it is not consistently performed,[5] which was a concern identified by the community prior to the start of the HELPS study.[10] Key learnings and recommendations from our study include:

1. Planning for dissemination during the initial stages of study planning can help ensure that appropriate methods of delivery, budgeting, and follow-up can be accomplished in ways that are meaningful to study team members and participants alike.
2. Establishing partnerships with key stakeholders in the community and investing efforts outside of typical study requirements demonstrates commitment to the CBPR process. Further, this investment builds trust with community members who may feel historically disenfranchised by studies that simply extract information of interest and fail to bring value back to communities.
3. Language used throughout the design, implementation, evaluation, and dissemination process within CBPR is important, particularly when the research topic focuses on health and wellness. Those in academic spaces may use language that is often not well understood by the community, which can make participating and asking questions intimidating. To counter this, all communications (printed word and pictures used) were reviewed by the research team, and CHW feedback was incorporated to ensure that content was culturally relevant and easily understood.
4. Trusting that the community of interest knows itself best and can identify resources, barriers, and processes better than outside members. Community members can provide key insights and bridges to help meet people where they are, ensure mutual understanding, and promote health and wellbeing within the community. This requires active and deep listening at each intersection between research and community participation.
5. Flexibility is paramount to success. While research is traditionally quite rigorous and rigid in its methodology, allowing for some adaptability throughout the CBPR process ensures that materials are tailored by the community of interest, for the community of interest. Our participants provided several thoughtful, creative, and unique ideas to help reach members of the community that we might not have been able to engage otherwise, which helped to increase visibility of the study, improve outreach and access to health information, and build important relationships with other key community partners.

Our study has several notable strengths. First and foremost, the HELPS study team was able to successfully develop trust by seeking continual feedback throughout the research process. This made the materials relevant and tailored to their needs in a way that was by the community, for the community, which ultimately improved the feasibility of the study. Additionally, by planning to include dissemination activities from the study's onset, the HELPS study was able to validate the results obtained from earlier phases. Further, it ensured that participants were engaged and eager to continue to share what they learned with others. It was evident that there was enthusiasm for learning about stroke and stroke prevention that would last beyond the study's conclusion.

We also noted opportunities for improvement. Namely, while Stroke Champions were comfortable with website navigation and content within it, additional support would have been beneficial to help answer questions that arise from the community specific to stroke. They also found that there was variable literacy in using resources and technology in the community. Stroke Champions noted that they needed more time to educate the community beyond the conclusion of the study's timeline. Study resources remain available, but the in-person support provided throughout the phases of the HELPS study was highly valuable and essential to the study's success.

Conclusions

Dissemination is an essential, but often missing, step in the CBPR process.[5, 9] The HELPS study successfully provided several avenues for sharing study results with participants and their community, thereby verifying and clarifying study results, providing additional education opportunities, and ensuring mutual understanding. Participants indicated that the HELPS study provided significant value for themselves and their community and reported eagerness to continue engaging with stroke prevention information and efforts. Use of the Community-Centered Dissemination Toolkit[12] was a helpful model in designing, implementing, and evaluating dissemination efforts to strengthen the HELPS study methodology and further build trust with research participants and their community. Future research should include dissemination as part of planning and implementation to promote true co-ownership in CBPR.

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*Please note: Links to and copies of the resources utilized by the HELPS study are available upon request.

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Table 1: Community Sharing Forum Responses

Question	**Sample Responses**
What does being a Stroke Champion mean to you?	*"I get to learn great information that can save someone's life."* *"An opportunity to inform our families and community."* *"It's important to me to <u>learn</u> and educate myself <u>and the community</u>."* *"Stroke Champion mean a lot to me because when I'm stressed I feel like am having a stroke with the systems (weighing) on me"*
What can make the Stroke Champions program better?	*"Us spreading the word and continued passing the info as well as education"* *"I believe in helping the community. Saving people lives through education, media, groups, etc. Going door 2 door networking"* *"More community awareness"*
What were the positives you got from this project?	*"Got to teach family and friends information that can save there life or their loved ones life"* *"Learning how to prevent some strokes"* *"Everything was positive because I needed to learn more about strokes"* *"Knowing about the numbers"*
What other questions or comments do you have?	*"With such high numbers of stroke in the black community, more aggressive info"*

Note: Comments have been transcribed verbatim, where possible, with only minimal edits for clarity.