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ABSTRACT

This project centers on the collaboration with grassroots community partners and a local safety-net hospital to create an appointment preparedness kit to help community members feel more empowered in medical spaces. The kit known as the “Empowerment Kit” consists of various questions that push community members to reflect on the purpose of their appointment, information/objects they need for their appointment, and help them identify barriers to care. The kit also links community members to the We Got Us website where they can find multilingual resources to help them learn about the management of common chronic illnesses. The creation of this kit was created with the direct feedback of community members and ultimately decided the direction of this project. This new tool could be utilized by community centers and organizations across the country to help us better learn about the needs of those we serve and how we can best support them.

BACKGROUND

The relationship between limited health literacy and poor health outcomes has been clearly delineated by researchers. Studies have shown patients with decreased health literacy are less likely to ask questions during clinic visits potentially leading to negative health outcomes. This poses a particular challenge for marginalized communities, such as racial and ethnic minoritized groups who disproportionately have limited health literacy compared to their white counterparts. This disparity is amplified when we consider other intervening factors perpetuated by systemic racism such as accessibility to adequate education, transportation, housing, and childcare². Communities with limited access to resources and the luxury of time, will be more likely to present to clinical visits unprepared because of the barriers they encounter.

Similar trends exist for marginalized groups in Boston and Cambridge, Massachusetts. In Boston, 24.2% of the population identifies as Black, however, 18% of Boston’s Black population lacks a high school degree compared to 4% of their white counterparts³. A 2015 study led by the Boston Federal Reserve Bank found that net worth Black Bostonians was \$8 compared to the \$247,500 net worth of white Bostonians⁴. Just across the river, in Cambridge, MA, 29.2% of residents identify as foreign born⁵. Considering how large of a role language accessibility, income status, and racial/ethnic minoritized status have on health outcomes, health interventions that promote equity for these groups are imperative.

OBJECTIVES

- Solicit community input to better understand the utility of an Appointment Empowerment Kit
- Better understand health topics community members would like to gain more knowledge about
- Creation of an appointment preparedness kit based off community input
- Trial appointment preparedness kit in the primary care setting to better understand the utility of this kit in practice
- Gain feedback regarding this utility from users and facilitators

METHODS

Phase 1

Working with WGU a community needs survey was developed to pass out at three community events in Roxbury, Mattapan, and Dorchester serving primary Black community members. Each person was given the survey (top left) in English and upon completion I used this information to develop the *Appointment Empowerment Kit* (bottom right and left) and worked with WGU team members to put together multilingual resources to complete the kit. Specific attention was paid to question 4 of the survey that assessed if community members would be interested in an appointment preparedness kit.

Phase 2

For the second phase I will pilot the *Kit* with Harvard medical students at the Cambridge integrated clerkship at Cambridge Health Alliance. This will help be get data about the effectiveness of the *kit* as each student work with a longitudinal complex primary care patients. Students will complete a survey to assess its utility and patients will be given a \$10 gift card to a Black owned restaurant as an incentive.

We Got Us Community Needs Survey
English Version

Instructions: If someone agrees to completing the survey and would like to do so verbally, collect their demographic information (categories listed below) and ask the open ended questions (listed below). Prior to reading the close ended questions, say the following: I am going to read some statements to you. I would like for you to tell me two things about the statement: (1) how important it is to you and (2) how satisfied you are with each service in your community on a scale of 1 to 4. 1 means very dissatisfied and 4 means very satisfied.

Demographic Information
Neighborhood: _____
Zip Code: _____
Age Cohort (circle one): Under 18 18-30 31-45 46-59 60+
Race (circle one): White, Black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander.
Gender: _____

Open-Ended Questions

1. What do you see as the greatest barriers to the health and wellbeing of your community - re. COVID and longer term?

Appointment Empowerment Kit Survey

Appointment Empowerment Kit Form

The We Got Us 'Appointment Empowerment Kit' was created to get a better understanding of how we can empower community members and patients to take more agency over their health during the time they spend with their doctors. Often times members of minoritized groups and communities feel intimidated in medical spaces because of the inherent power dynamic that exists. We Got Us is taking steps to help eliminate that and your participating in our evaluation of this tool is a big part in helping make that happen.

Please go to our website at wegotusproject.org to find the form which can be used by your patient prior to completing this form.

APPOINTMENT EMPOWERMENT KIT

Visits with your doctor are meant to help you achieve your health goals and provide healing for you to become your best self. That's why We Got Us created this kit to help you feel confident and empowered during your next visit. Fill out as many spaces as you can and if you have questions, use the QR codes to find new resources to help you get the most out of your visit.

Purpose of my appointment:
Ex. general check up, follow up my diabetes

Things I need to bring my appointment:
• Logs (blood pressure, blood sugar, dietary)
• Previous records (imaging, hospital records)
• Medications
• Other _____

Things I'd like to know before my appointment:
Use this QR code or visit wegotusproject.org to find information about health topics including:
• Diabetes and high blood sugar
• Hypertension/high blood pressure
• Maternal health and birthing
• General wellness tips

Challenges I've had leading up to my appointment:
• Transportation
• Understanding my diagnosis
• Affording medication
• Affording food
• Accessing internet for televisits
• Other _____

Things I want to clarify at my appointment:

Were all my concerns addressed?
• Yes
• If not, list here _____

HERRAMIENTAS PARA SU CITA

Visitas con el doctor son para ayudar lograr sus metas de salud y proveer lo que necesita para convertirse su mismo en lo más saludable posible. Por eso "We Got Us" ha creado esta página de recursos para ayudarse sentir más confianza y empoderamiento durante su próxima visita con el doctor. Llene lo más espacios posible abajo y si tenga preguntas use la cámara en su teléfono para escanear el código para visitar nuestra página web donde tenemos más recursos sobre varios temas sobre la salud.

Motivo de mi cita:
Ejemplo: visita general, seguimiento para la diabetes

Cosas necesito traer a mi cita:
• Páginas con niveles recordados de presión etc.
• Registros pasados (de hospital, imágenes)
• Medicamentos
• Otra: _____

Cosas me gustaría aprender antes de mi cita:
Use este código o visite wegotusproject.org para encontrar información sobre varios temas de salud incluyendo:
• Diabetes y azúcar alto
• Hipertensión y la presión alta
• Salud maternal y parto
• Consejos para bienestar general

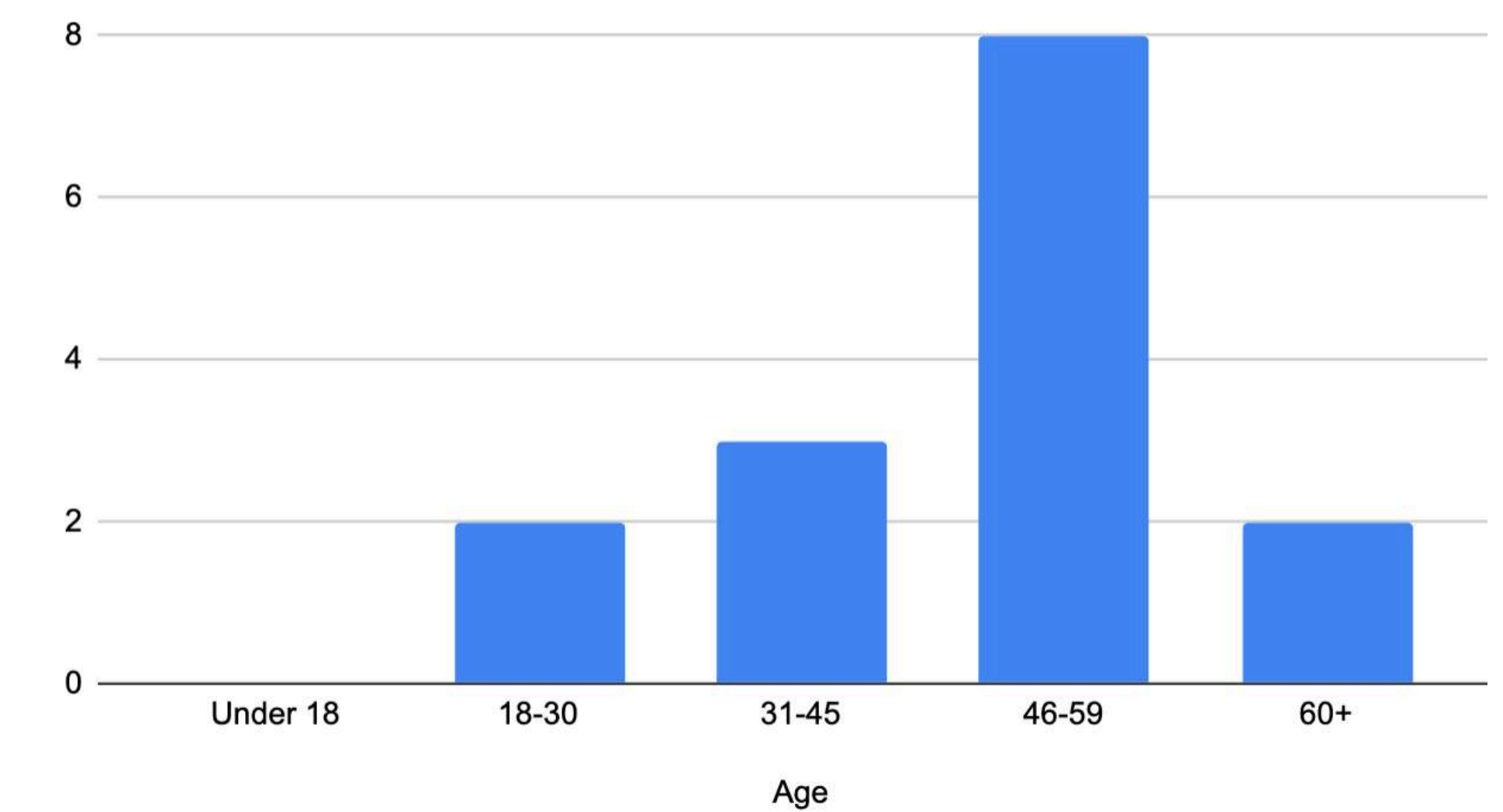
Dificultades he tenido antes de mi cita:
• Transporte
• Entendiendo mi diagnóstico
• Pagar por mi medicamentos
• Pagar por comida
• Acceder internet para mi citas en la red
• Otra: _____

Cosas me gustaría aclarar antes de mi cita:

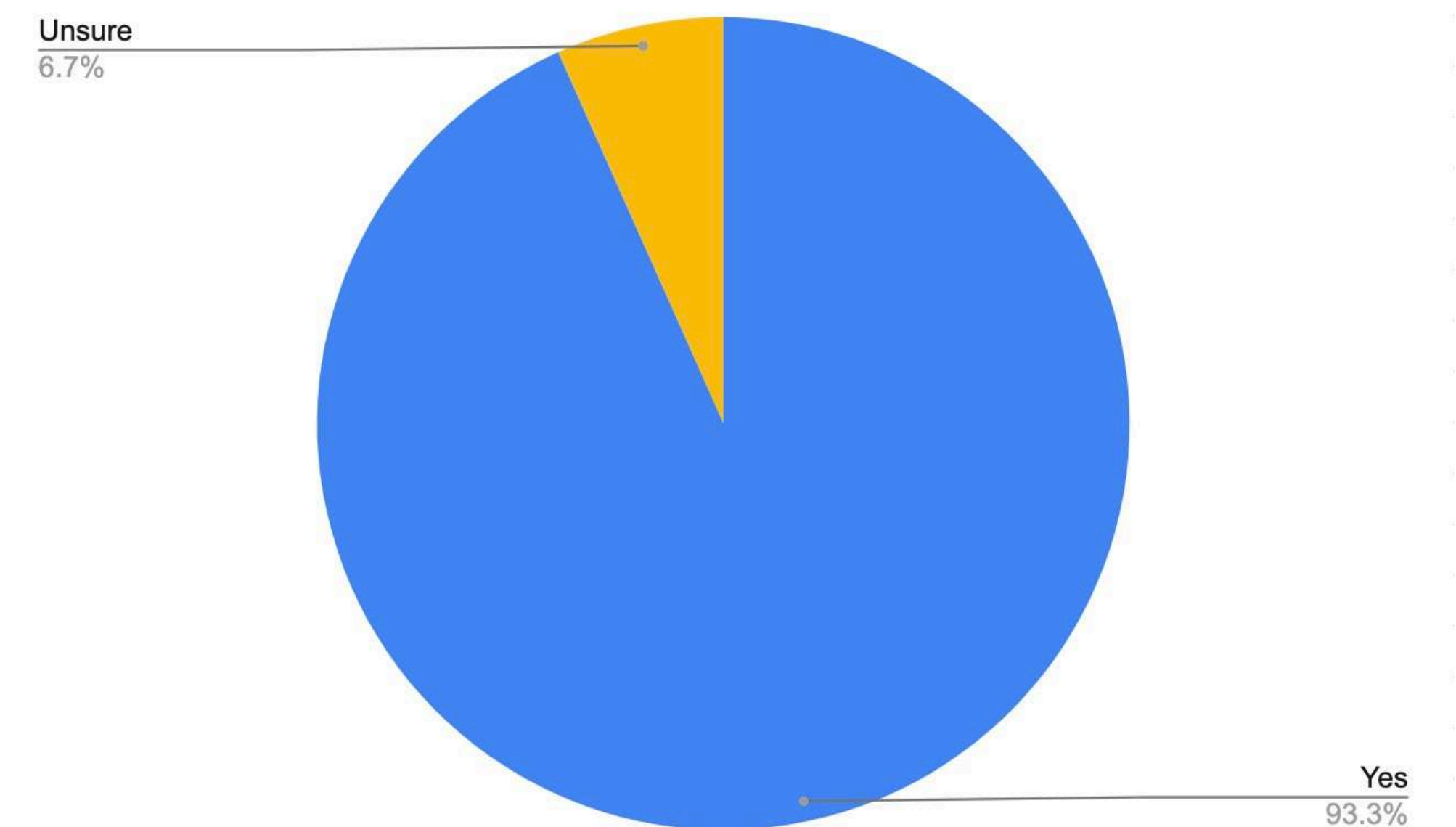
Todas mis preocupaciones y preguntas fueron aclaradas durante mi cita?
• Si
• Si no, ponga las equi _____

RESULTS

Age Range of Respondents



Unsure



RESULTS

Findings from the initial survey was significant for three primary themes emerged: 1.) a desire to learn about health topics including diabetes, hypertension, mental health, and maternal health 2.) folks experiencing homelessness were interested in learning about support for housing access and substance use disorders 3.) a desire to have more clear guidance how to get access to primary care. Using the preliminary data we got from these surveys I then created the We Got Us *Appointment Empowerment Kit*. Nearly all respondents replied, “yes” with one being “unsure” (Chart 2) demonstrating a clear interest in this type of resource. Of the respondents most identified as women and were of the 46–69 age range (Chart 1).

CONCLUSIONS

- There is clear interest in Black communities in Boston about the creation of an appointment preparedness kit that would help them take more agency in medical spaces.
- There are clear gaps in medical education for marginalized communities in Boston and people are interested in learning about various chronic disease management, in addition to resources for mental health and substance use support.
- When doing work in the community it is important to get community input first. Of note, our initial survey was only available in English and this may have biased some of our initial data. In the future it will be key to survey more community members in more diverse communities across both Cambridge and Boston.
- More research is needed to better understand the utility of the *Kit* during clinical visits