Material A. Volunteer implementation guide used to collect patient interviews for narrative medicine project at a student-run free clinic

Phillips Neighborhood Clinic Narrative Medicine Project Volunteer Implementation Guide

Site Details

The Phillips Neighborhood Clinic Patient Narrative Project is an effort to engage patients and understand their experiences at PNC, in healthcare, and in their lives. The project involves recording short interviews with willing patients and transcribing the interview into a written narrative. The stories are then shared back with patients and may be used (with patient permission) in PNC quality improvement initiatives and volunteer education.

As a volunteer, you will be present at PNC on clinic nights to recruit and converse with patients about their healthcare experiences. You will record your short conversation with the patient, then pass along the audio recording to the Patient Engagement Coordinator, who will transcribe the story and use it for further applications at PNC. Detailed information about how to run a Patient Narrative Project volunteer shift is outlined on page 3 of this document.

Shift Details

Patient Narrative Project volunteer shifts will run in-person on clinic nights (Monday and Thursday) from 6:30-8:30pm. Please wear business casual dress or scrubs and appropriate PPE (mask & face shield).

Signing up for and Documenting Shifts

Space is limited to 10 volunteers. After signing up on this form [link], the Patient Engagement coordinator will email you to schedule a 30 minute group training session prior to starting your volunteer shifts.

Details about signing up for clinic shifts

- Shifts run at PNC from 6:30-8:30pm on Monday and Thursday nights
- Sign up for and document volunteer shifts on the Patient Narrative Project Schedule [link]

Questions or Concerns?

[Coordinator Name, Role Title] [Email Address]

Description of Shift Duties

- 1. Arrive at PNC for your shift by 6:30pm in appropriate attire, name tag, and PPE.
- 2. Inform the clinic coordinator and reception volunteers what you will be doing in clinic tonight and that you will be located on the stage if they have any questions.
- 3. Gather materials necessary for Patient Narrative Project shift:
 - a. Blue folder labeled "Patient Narrative Project"
 - i. Located within the Reception file cabinets
 - b. 2 chairs (set these up on the <u>stage</u> in the waiting room / gymnasium area)
- 4. Recruit patients to share their stories
 - a. If your patient is Spanish-speaking and wishes to participate but you do not speak Spanish, you may ask the undergraduate interpreters for help translating during your conversation
 - i. Undergraduate interpreters sit located behind the reception desk area
 - b. <u>Note</u>: Not all patients will be interested or able to participate in the project -- that is ok, but please do your best to recruit willing participants. This is a fun chance to communicate with patients in a way we may not normally get to as volunteers!
- 5. How to recruit interested patients:
 - a. Feel free to wait in the stage area and keep an eye on incoming patients.
 - b. Once patients have completed their reception paperwork and are waiting for their appointments in the waiting room, approach them and explain/ask about their participation in an interview.
 - i. <u>Note</u>: a general script/outline for **how to recruit patients** is included in this document (see below)
- 6. Conduct the interview with your patient:
 - a. First, reiterate the purpose of the Patient Narrative project.
 - b. Second, review and complete the Consent Form with the patient.
 - i. Ensure proper consent procedures are followed and assure the patient that their comfort and confidentiality are our top priority
 - ii. Ask the patient if they'd prefer to read the form themselves or have you read it to them. Have the patient complete the consent form (in English or Spanish).
 - c. Conduct the interview and audio record it with your phone.
 - i. For tips on interview collecting, see below
 - ii. In terms of logistics, it would be best to close the stage curtains for privacy and better audio for the recording. You may want to also test recording yourself on your phone prior to the actual interview to make sure the recording will be audible.
 - d. After the patient shares their story, please ask them two important follow-up questions:
 - *i.* Was it helpful to share your story? If so, what was helpful about it / why?
 - *ii.* What do you hope will be accomplished by sharing your story with PNC?

- e. Collect the contact information of the patient so we can follow-up about the final story summary via email or other formats.
 - i. <u>Only do this step</u> if the patient indicates they would like to receive a copy of their story during the consent form process.
- f. Give the patient a [amount] gift card! (one card per patient)
 - i. Complete the Gift Card Tracker sheet prior to dispensing the gift card to the patient (hard copy to fill out located in the blue Patient Narrative folder)
 - ii. Gift cards can be found in an envelope filed in the Patient Narrative Project folder
- 7. At the end of your shift (8:30pm):
 - a. Put away chairs
 - b. Return blue "Patient Narrative Project" folder to Reception file cabinets
 - i. File any completed consent forms from the night on the side of the folder labeled "Completed Consent Forms"
- 8. After your shift:
 - a. <u>Upload</u> the audio recording of the interview to the [Secure storage environment] (this is a secure way to store the file, which may contain personal patient information)
 - <u>Share</u> the audio file from your [Secure storage environment] account with the Patient
 Engagement Coordinator ([Name]) at [email address]. Label the audio file: Patient Narrative (date) patient # (1, 2, 3, etc depending on how many interviews you conduct)
 - c. Create and share a document containing the patient's contact information if you gathered it during the interview. This information will be used to share back the written story with the patient if they would like.
 - d. The Patient Engagement Coordinator will email you after receiving the shared audio file -- please <u>delete the audio file and contact information document</u> after receiving this email.
 - i. Please do not delete the file before receiving this email (so we can ensure we are able to access the audio file through [Secure storage environment])
 - ii. <u>Key</u>: Make sure you delete the file on your phone and document with contact information after receiving this email to ensure patient privacy!
 - e. After sharing, your job is complete.
 - i. The Patient Engagement coordinator will then transcribe your interview to share back with the patient and potentially use for future improvements at PNC.

General Recruitment Outline

- Hi there -- I know there have been a lot of people coming up to you and asking you questions so sorry to keep bothering you! My name is XXXXX, I am one of the student volunteers here. At the PNC we are trying to do a better job of listening to our patient's stories with health, healthcare, and illness. We setup an area on the stage over there where we are recording patient stories. It is completely confidential, anonymous, and you can receive a \$10 gift card for participating. Would you be at all interested?
- If yes: Great. It usually takes about 20-30 mins after you arrive for them to come see you, do you think your story will be pretty short (<5 min)? If so, maybe we can do it before you're seen by the healthcare team. If not, you can come find me once you are done I'll be on the stage.
 - <u>Note</u>: If you conduct the interview before the healthcare team comes to get the patient, let the registration desk know so that they can let the health care team know the patient will be done in a few minutes.
 - <u>Note</u>: If you do the interview later, you can keep an eye out for the patient at the pharmacy waiting area periodically.
- If no: No problem. If you change your mind I'll be on the stage area until 8:30pm tonight.
- If maybe: You can think about it and see if anything comes to mind. I'll be on the stage area until 8:30pm tonight.

Tips on Conducting Patient Interview

- Purpose of this project: to learn about patients' experiences life experiences
 - o Stories can be as short or long as the patient wants!
 - This does not need to be formal or structured -- the point is simply to learn more about the lives of the patients we serve at PNC
- Some questions if your patient doesn't know what to say:
 - In the past, patients have shared some of their life experiences or stories that they wanted students at the clinic to hear about. Some people have talked about what it was like to find healthcare after immigrating, others talked about giving birth, or losing a family member. It can be anything you want really.
 - o What are some good or frustrating experiences you have had in healthcare?
 - What have your experiences at PNC been like?
 - Are there any things you have especially enjoyed? Things that you would like to see changed?
 - What do you hope that students at PNC will get from learning about your story?

Material B. Facilitator's guide and patient narrative used for narrative medicine educational session at a student-run free clinic

Phillips Neighborhood Clinic Narrative Medicine Educational Session (Volunteer Orientation) Facilitator's Guide

DESCRIPTION

The PNC has recently started a *Narrative Medicine* program to gather the stories of our patients. During Orientation, we will be breaking volunteers into groups to give volunteers a window into patients' lives beyond clinic walls, followed by group discussion.

The objectives of this exercise are to:

- 1. Describe some of the strengths and challenges that patients may carry with them prior to arriving at clinic.
- 2. Discuss how the perspectives and skillsets of the different health professions can holistically meet the needs of PNC patients.

SET-UP

- 1. This activity is designed to be completed in 20 minutes. Rough timeline:
 - a. 0:00-2:00: Getting settled, introductions, buffer time
 - b. 2:00-5:00: Read narrative, either popcorn style or silently (see what group would like)
 - c. 5:00-18:00: Group discussion
 - d. 18:00-20:00: Overall wrap-up/reflections from the facilitator
- 2. Groups of ~10 students will participate in each discussion the optimal size for small group discussion. Each group will have a facilitator that can briefly describe the exercise and facilitate conversation.
 - a. Ideally, volunteers should be numbered off so that they are not grouped with too many people from their own program.
- 3. Facilitator's questions are provided below as a guide they do <u>not</u> need to be followed verbatim and you do <u>not</u> need to use all (or any) of them. The goal is to let participants speak and reflect for most of the time; use the questions when there is a lull.
 - a. Facilitators should try and elicit perspectives from as many group members as possible. Using techniques such as saying "can we hear anything from this side of the group" or calling out generic professions (e.g., "those of you who work more on the medical side") can encourage conversation while not cold-calling people.
- 4. Facilitators should let participants know from the onset that the narrative is authentic and was shared with the permission of the patient. It must still be treated with respect.

PATIENT NARRATIVE

My counselor recommended this clinic [PNC] to me so that I could have a tooth pulled out. So, I was kind of disappointed to find out that you don't do that here. I had to drive quite a way, with poor instructions from her. But that's not your fault. And at least I got some information about where to go.

I'm 33 years old and living in a halfway house. I'm currently sober, but it's a constant struggle. I've had a rough life, and honestly, it's amazing that I'm even still alive. A few months ago, I punched a guy and was charged. At that time in my life, I was using meth, cocaine, marijuana, and alcohol. It was my birthday night, I was drinking

and using cocaine. It started because he was talking down women, he is a scummy person. Then he lied and told my coworkers that I was trying to sell him meth in the bathroom when he was actually asking me for cocaine all night. And things just got out of control. In that exact moment when I hit the guy, I saw where my life way going... drugs, jail, and death.

So I did my time, and I'm finally back in line with the law now. If that hadn't happened, I would probably be dead by now from overdose or some other result. But since this all happened, I realized that I didn't want this kind of life. I don't want to use and doing time gave me some resources to quit.

I was sober for 4 months when I last slipped, I was so filled with shame and disgust. I was so disappointed with myself. But that didn't stop me from continuing even as I felt ashamed. And that's addiction for you, when you're crying even as you are using.

I want to stay clean. I'm working on not being so hard on myself. I mean things were going so well, I was sober, I was working, straightening out my life. But you know, that's when I relapsed. Things were going so well and then I was offered position to be a mentor and all these other responsibilities... and it was too much. It overwhelmed me.

I don't see myself as a 'desk job" worker. I always saw myself doing something with my hands, making something or fixing something.... But maybe this is what I was called to do. Maybe I'm meant to fix people. To mentor people and help them get off drugs.

My dad died a year ago and his wife just died recently. I went down by the river to make my peace and two eagles fly over my head. I get goosebumps just talking about it. One flew by real close and looked me in the eye and then reunited with the other. It was like they were happy to finally see each other after that year. And I wasn't able to settle our problems before she died, so it was incredible to experience that.

My dad was also an addict, and he ended up being my mentor. Which was great, he understood, and I was able to tell him everything. I wear a necklace with his fingerprint on it. It says "Love ya" because he was always saying that, to everyone.

I want to prevent others, especially young people from using. I mean, drugs are bad. They can ruin your life. You don't want to end up like me, 33 years old and in a halfway house.

FACILITATOR'S QUESTIONS

- 1. What are your **initial reactions** to reading the story? How did it make you feel?
 - a. Probe: What parts of the story particularly stuck out to you?
 - b. How did this story make you feel? Do you have any biases?
 - i. anxious, angry, etc?
 - c. How would deal with a patient story, like this, that makes you uncomfortable?
- 2. What would you identify as this patient's primary needs? What services might benefit him?
 - a. Probes:
 - *i.* Think about the degree program you are in right now. What are some things you are learning in school could help this patient? Where are the limits of your profession where you might need to bring in someone else?
 - ii. Medical and pharmaceutical:

- 1. This person has struggled with addiction and might benefit from <u>treatment</u> <u>medications</u> for opioids (e.g., Methadone, Buprenorphine) and alcohol (e.g., Disulfiram, Naltrexone).
- 2. This person mentions ideas of self-disgust and shame, talks about how his addiction has "ruined [his] life", and had his father pass away in the past year. Collectively this may put him at risk for depressive symptoms. He may benefit from medications like <u>anti-depressants</u> or <u>mood stabilizers</u>.
- iii. Allied health:
 - 1. Occupational therapy can help with skills such as <u>stress management</u> so that the patient can better manage emotions in response to stressors, as well as other means to manage daily situations without resorting to drugs.
- iv. Behavioral health:
 - This person has struggled with addiction and could benefit from <u>behavioral</u> <u>therapy</u> to deal with cravings and prevent relapse (e.g., cognitive-behavioral therapy, contingency management).
 - 2. This person mentions ideas of self-disgust and shame, talks about how his addiction has "ruined [his] life", and had his father pass away in the past year. Collectively this may put him at risk for depressive symptoms. He may be benefit from being <u>screened for depression</u> or other mental health conditions, or from <u>counseling</u> to support his mental health.
- v. Social and legal services:
 - 1. This person was previously incarcerated, which may present challenges for him in accessing <u>housing</u> and <u>employment</u>. Relatedly, he may also need <u>legal</u> <u>services</u> to support his re-entry into the community.
- 3. What would you identify as this patient's primary strengths?
 - a. Probes:
 - i. A strong desire to stay clean, and previous evidence that he has the ability to remain sober.
 - ii. Currently working as a mentor for other people with addictions, which he feels is his calling ("Maybe I'm meant to fix people".)
 - iii. Memory of his father's mentorship and support.
 - iv. Strong sense of values he got into a fight, but it was because someone else was treating women poorly.
- 4. How does this exercise influence how you approach your volunteer role?

WRAP-UP

Remember that this is just one story among many experiences we will encounter here at PNC. We may only get to see the "tip of the iceberg" of patient lives, but we hope this exercise helps us reconnect with what brings us to the helping professions in the first place: to bear witness to the joys and challenges of people's lives, and to use the tools of our professions to move people closer to well-being. Thank you for taking the time to engage in this activity.