

Peer Outcomes Protocol Project

Peer Outcomes Protocol (POP): Administration Manual

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POP Administration Manual

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Introduction

In 1996, the University of Illinois at Chicago National Research and Training Center (UIC NRTC) on Psychiatric Disability (www.psych.uic.edu/uicnrtc), together with the Missouri Institute of Mental Health (www.mimh.edu/mimhweb/mimh), began the Peer Outcomes Protocol Project (POPP). POPP was funded by the U.S. National Institute on Disability and Rehabilitation Research and the Center for Mental Health Services. Jean Campbell, Ph.D, headed this project. It was designed to develop, field test, and distribute a way to evaluate mental health peer support programs or groups that are based in communities, including those that are run by mental health consumers. "Outcomes" are things that happened to the participants because of the program or group. POPP is a step-by-step guide for gathering information about the program or group, including a questionnaire to use. This questionnaire includes many questions to ask participants, such as what the participants are like, what things they need from peer-run services, and how satisfied they are with peer-delivered support.

The Peer Outcomes Protocol (POP) Administration Manual explains the Protocol and its sub-parts. Each sub-part is called a module. This manual highlights how to prepare for conducting the interview. Section One gives an overview of the POP questionnaire and describes all of its parts. Section Two offers advice on how to prepare for the interview, how to prepare the respondents and interviewers (especially for sensitive sections), how to read the questions, and how to code the responses. Section Three covers what to do after an interview has been completed. It also suggests ways to use the results to improve the quality of life and peer supports for people with psychiatric disabilities.

Section 1

OVERVIEW OF THE PEER OUTCOMES PROTOCOL

Why Study Peer Outcomes?

It is important to study the outcomes of peer support so that it can be as helpful as possible. The use of self-help and peer support has become very popular over the past twenty years. Peer support is based on the belief that people with a shared life circumstance come together to help themselves and each other. By coming together and sharing practical strategies to manage problems, people feel less isolated, are more empowered, and often have less need for formal services. However, we still have more to learn about the value of peer support for people with mental health difficulties, and the POP is one tool that can help with this.

It also can help you answer what may be the most important questions for you: How is your program or group doing? What are your members like? What do they need? What does your program give them? How satisfied are they? Before your program decides to use the POP, it should decide what it wants to learn, what information it needs, and what it will do with that information once it has been collected.

POP Modules.

The Peer Outcomes Protocol consists of seven parts or modules:

Demographics Module
Service Use Module
Employment Module
Community Life Module
Quality of Life Module
Well-Being Module
Program Satisfaction Module

The interview starts with a brief overview of the purpose of the interview and the types of questions that will be asked. The person being interviewed (also called a “respondent”) is reminded that all answers are confidential and that participation is voluntary. The interview takes about one hour to complete and breaks should be taken, upon request. The Protocol has an accompanying set of Response Cards, as described in more detail in the next Section.

The ***Demographics Module*** includes 21 items about such things as a person’s date of birth, gender, race/ethnicity, country of origin, marital status, parenting status, level of education, and financial resources. This background information helps in understanding the people in your program. It will also help when analyzing and understanding what you find out, and deciding what to do next.

The ***Service Use Module*** contains 32 items, including questions about a person’s mental health history, his or her past use of community-based and inpatient services, and the usefulness of peer support before, during, or after hospitalization. In particular, these questions help determine the value of peer support in dealing with one’s mental health difficulties and psychiatric hospitalizations.

The ***Employment Module*** asks about a person’s past and current work experiences. The 24 items include questions about employment status, wages, interest in work, and the value of peer-delivered services in supporting one’s desires to work and managing one’s concerns about it.

Items in the ***Community Life Module*** gather information about a person’s housing situation and community life. Respondents answer 50 questions about their current living arrangements, activities of daily living, satisfaction with their neighborhood, social relationships,

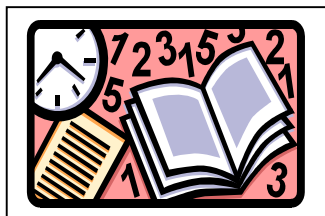
any experiences of discrimination, encounters with crime or violence, and levels of social acceptance based on a diagnosis of mental illness.

The *Quality of Life Module* contains 28 questions about people's daily life experiences. Questions ask about physical health and activity, emotional problems, life satisfaction, and how peer support has affected people's quality of life.

Questions in the *Well-Being Module* ask about a person's sense of identity and self-esteem. This section also covers whether peer support is helping the individual to become more self-sufficient, is giving him or her more control over life, and is promoting recovery from mental health difficulties.

Finally, the *Program Satisfaction Module* contains 50 items asking for opinions about the peer support program or group. Items address whether peer support has helped members to meet their employment, housing, education, transportation, human rights, and cultural and gender-related needs. The module also asks opinions about peer staff, comfort with other program members, and experiences with any mental health services the person may have received.

The interview concludes with an open-ended item that allows the individual to share any thoughts s/he has about the questionnaire. As described in the next Section, the Protocol is accompanied by a Question-by-Question Guide, which provides directions for how to read each of the questions in the instrument. It can be used as a guide for new interviewers and as a reference for more experienced ones.



Why Use Modules?

The Peer Outcomes Protocol is organized into 7 major parts, or modules, for two major reasons. The first is because, when developing the instrument, it was found that individuals have specific needs in a number of life areas. Organizing the items into larger areas of concern makes the POP easier for you to administer and easier for respondents to understand.

Second, by organizing the Protocol into sections, it will be possible for your program to administer only those items that are relevant to your program. For example, a peer-run drop-in center may decide that the employment module is not relevant because they do not offer vocational services. Therefore, they could eliminate this module from their assessment. To use the Protocol in this way is perfectly acceptable, as long as there are appropriate reasons to omit certain questions. To decide not to administer a module – let’s say Community Life – because it has questions the interviewer finds embarrassing (such as items regarding crime, violence, or abuse) is not an appropriate reason for avoiding certain questions. This is why it is so important to understand before you start why you want to use this Protocol, what you hope to learn, and what you plan to do with what you find out.



Section Summary.

The goal of the Peer Outcomes Protocol (POP) is to help peer-run programs or groups gather information that they can use to become as helpful as possible to their members. The POP is divided into sections for easier use, and so that programs can ask about outcomes that are relevant to the kinds of peer support they provide.

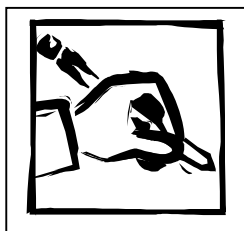
Section 2

ADMINISTERING THE PROTOCOL

Introduction.

This Section will discuss how to administer the POP. It includes:

- ✓ why your program might want to use the POP
- ✓ what approach to take
- ✓ how to prepare for the POP
- ✓ how to maintain confidentiality
- ✓ how to read the questions, use response cards, and code responses
- ✓ how to prepare the respondent and the interviewer for sensitive items
- ✓ tips for administering the POP



Reasons to Administer the Protocol.

Some organizations will use the POP for *program development* purposes to obtain information on the needs of members. This often includes finding out what new services or supports would be of help. The POP also

can be used for *program evaluation* or *research* purposes, to improve services or show that the program is helping people. Still others may use the Protocol as a *policy development* tool to demonstrate to policy makers that peer members have needs that have not yet been met. This use might convince policy makers to fund the program to meet these needs. The multi-purpose potential of the POP is one of its strengths. It is important, however, to decide how the information will be used before you start. This decision will influence the kinds of information you gather, as well as the usefulness of this information.

Using an Informal versus Formal Approach.

The Peer Outcomes Protocol is meant to be administered as an interview, under the guidance of an interviewer. It is not recommended that the questionnaire be handed out or mailed to program members to fill out on their own. If an interviewer is not present, it is possible that the respondent would not understand all the questions. With no interviewer present, the respondent might answer questions incorrectly. Also the questions are worded in ways that make sense only if on person is reading them to another. They are not worded in the “first person,” (i.e., me or mine), but in the “third person” (i.e., you or yours).





The recommended approach is to have an interviewer use the POP with a peer, individually and in private. If this is not possible because of time or location, a group method can be used, although this is not desirable. For this method, an interviewer would pass out questionnaires to the group, read the questions out loud, and have each person write his or her own answers on a copy of the questionnaire. If anyone has questions, the interviewer would answer and clarify. If a group method is used, it is very important to protect the confidentiality and privacy of the information. That is, the respondents should be seated so that people cannot see each other’s answers.

Guarding Against Bias.

You will to be sure that the information you gather is as accurate as possible. To do this,

you need to be very careful not to bias the information collected. As used here, the term "bias" refers to the fact that some people might feel pressured to answer in ways they think will please the interviewer. This is called a "positive response bias," and means that some people may say good things about the program, regardless of how they really feel. They may be afraid to hurt people's feelings by saying that certain services or supports are unneeded or that some of their needs are not being met. Bias also could result if participants feel compelled to say good things about the program because they are enjoying refreshments that have been provided during the interview. Another bias might result if peers worry that they will lose services or supports if they mention problems with those services, or if they say they need additional assistance.

Whatever the potential sources of bias, you will need to design a POP administration plan that avoids biased results. Consider doing the following...

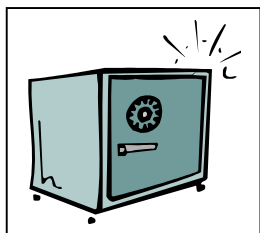
-  Tell people that it is okay to say negative things during the interview. Encourage them to tell the truth, even if that means complaining about the services, the larger organization/program, or anything that is being asked about.
-  Serve refreshments at the end of the interview so no one feels obligated to respond favorably because they received food.
-  Remind respondents that their answers are confidential and will NOT affect the assistance they are receiving.
-  Emphasize that you are as interested in identifying needs that have not been met as well as those that have been. In addition, you might express an interest in knowing whether some people are receiving too much assistance or feel forced to accept help they don't need.

Practical Preparations.

It is best to gather everything you need to administer the Protocol before you start. This includes having enough copies of the Protocol, and making sure that every copy is complete and that all pages are legible. Make sure that you have enough pencils (better than pens so that people can change their answers if they wish) for every person. You also should have extra copies of the questionnaire and extra pencils available. Make sure that you have the Response Cards for the survey participants to use. If you are administering the Protocol to a group of people, make sure that you have reserved a room that is large and quiet enough. Visit the room in advance to make sure it suits your purposes.

Preparations Checklist

- | | |
|-----------------------------------|--------------------------------|
| ✓ Protocols (with extras on hand) | ✓ Suitable room |
| ✓ Pencils (with extras) | ✓ Refreshments, if appropriate |
| ✓ Response cards | |

Maintaining Confidentiality and Privacy.

If you are administering this Protocol in a mental health services program, you probably will need to take each person you interview through a process of *informed consent*. This means that you must:

- explain in detail why you are administering the Protocol,
- address exactly what the respondent's participation will involve,
- respond to all of the respondent's questions, and
- ask him or her to sign a consent form.

Once you both sign this consent form, you also will sign on the Protocol's cover page, where it says, "Informed Consent Signed." This allows you to double-check that you have fulfilled your obligation to fully inform the person about the interview, what the person can expect, and his/her rights as participants.

The information that you collect must be treated with respect. All information must be kept private and confidential. This cannot be overemphasized. You should explain that people's responses will be kept in a safe place, such as a locked drawer or file cabinet, and that nothing they say will be shared with others. By doing so, you will earn each person's trust. A good rule to follow is to always treat others' personal information like you'd want your own personal information to be treated – with great care and discretion.

Using Research Numbers.

Ideally, all information should be collected and stored in a way that prevents anyone from identifying how certain individuals answered the questions. The goal is not to find out how Person A or Person B answered. The goal is to find out how a number of participants answered; for example, how many said "yes" and how many said "no" to a particular question. To help do this, the Protocol has a cover sheet that allows you to record the respondent's identification (or ID) number. You can choose what number to use here, but it should be something that could not be easily linked back with the person. For example, you wouldn't want to use the person's birth date as his/her ID number, but you could use the last four digits of his/her phone number or social security number.

While you want to keep the individual responses confidential, you also need to keep a "master list" of the people you wish to interview, so you can keep track of who has been interviewed thus far and who has not. This list can contain the names and telephone numbers of people to be interviewed. It can be used to make appointments with them for the interview.

Once interviewed, a person's name should be checked off, so that it is clear that he/she does not need to be contacted again.

If you are administering the POP at more than one location, the cover sheet also includes space for a site identification number. Finally, if you have more than one interviewer, the cover sheet also allows for each interviewer to record his or her own identification number.



Reading the Questions.

When beginning an interview, you should reassure the respondent that there are no wrong or right answers. As an interviewer you must:

- Read questions exactly as they are worded in the questionnaire.
- Read questions in the order in which they are presented on the questionnaire.
- Ask every question on the questionnaire (unless there are skip instructions or it was decided in advance to leave out some questions because they aren't relevant). After reading the question, listen quietly and patiently for the response. Do not interrupt or make a comment before the respondent has completed an answer.
- Read questions with no additions, deletions, or substitutions.
- Read each question slowly at about two words per second. This is slower than most people speak, so be sure to practice reading at this slower speed.
- Use a tone of voice that conveys assurance, interest, and a professional manner that is neutral and non-judgmental.
- Emphasize underlined words to enhance meaning.

Do not attempt to re-word or explain a question. If the respondent does not understand, repeat the question slowly or look to see if there is an explanation given for this question in the Question-by-Question (QbyQ) Guide. **To ensure that all interviewers use standardized responses to questions (which means that each interviewer should use the exact same wording), interviewers should read the shaded and italicized explanations exactly as they are written.**

For example, one question reads, “What ethnicity do you consider yourself to be?” If someone asks you to explain the question further, you would read the shaded explanation from the QbyQ. If the respondent continues to ask what it means, you would reply, “Whatever it means to you.” The QbyQ Guide contains further information you may need to answer questions. You should have it with you during the interview and refer to it whenever necessary.

Sometimes a respondent will want to answer a question before you have finished reading it. It is important that the respondent hear the entire question before answering. If someone interrupts, you must continue reading the question. This allows the respondent to hear the entire question, and it also discourages future interruptions.

Don't skip a question because the answer was given earlier or because you think you already know the answer. In those situations where the respondent has already provided information that probably answers the next question, you may preface the question with some combination of the following phrases:

- “I know we've talked about this,” or “I know you just mentioned this, but I need to ask each question exactly as it appears in the questionnaire.”
- “You have already touched on this, but let me ask you. . .”
- “You've already told me something about this, but I'd like to ask you. . .”

Do not assume that information you got earlier, in passing, is the correct answer to a later question in the interview. Also, do not direct someone by mentioning an earlier answer. If an answer is different from the one you expect, do not remind the person of an earlier remark or try to force consistency. Finally, remember that, although you may have read these questions many times, the respondent is hearing them for the first time and needs time to understand the questions and decide on the answers. It is very important to read each question slowly.

Using Response Cards.

There are a number of questions in the POP that have more than four or five responses. It is too difficult for most people to remember all of these choices. For this type of question, a response (scale) card is supplied with the reply choices listed on it. Each of these questions will tell you which card to use. Before you read the question, hand the card to the respondent. Read the question, asking the respondent first to look at the response card as you read the responses, and then to choose one answer from the card. In a few instances, respondents are asked to select more than one answer for a particular response card, if more than one answer applies. You will use a response card packet, so that you can flip to the appropriate card to display to the respondent. If you are interviewing a group of people at one time, you should have a separate set of response cards for each person.



Coding Responses.

The respondent's answers must be completely and properly coded on the questionnaire, or the interview results cannot be used for analysis. Record every answer in the appropriate category. Do this by circling the **number** of that category, which is either to the right of the category or below it. Sometimes you will be asked to write an answer on a line instead. If the respondent selects an "other" category," you should be sure to circle that category number, and then, write the respondent's explanation on the line provided.

Some respondents don't like to make choices, such as deciding whether they "agree" or "somewhat agree" to a survey question. While we do not want to force anyone to answer a question, we also do not want to accept "don't know" answers if we feel that someone has not thought about the question. Before accepting a "don't know" as a final answer, ask the person which choice comes closest to how he/she feels. Repeat the question if necessary. If the person still says "I don't know," write that down next to the other categories. If the respondent refuses to answer a question, remind him/her that the information is confidential. If the person still declines to answer, write "refused" next to the question.

Preparing the Respondent for Sensitive Items.

It is a good idea to caution participants in advance that they may consider some of the items in the POP to be personal or sensitive in nature. These items ask about topics such as financial circumstances, mental health history, and trauma. When telling participants that they may be faced with some difficult questions, it is helpful and appropriate to clarify your reasons for asking. For example, you might note that you are asking about personal information not because you're "nosey," but because you care about aspects of their lives that many people ignore, and about which little is known.



Again, it is important to make it very clear to respondents that they can skip any item. It also is necessary to inform them that they can stop responding to the Protocol at any time they wish, by either taking a short break or discontinuing the survey.

In addition to preparing respondents for sensitive questions before and during the interview, plan for a “debriefing” as described below after the interview has been completed.

Administration Tips.

- DO be very organized by having all of the materials you need to administer the POP prepared in advance (in other words, extra copies of the questionnaire, extra pencils, response cards, QbyQs).
- DO visit the room you will be using to conduct the interview, if applicable, to be sure it meets your needs.
- DO provide an accurate and easy-to-understand explanation of why you are conducting the Protocol. People have the right to know why you are asking them these questions and how their information will be used.
- DO emphasize that answering the questions is totally voluntary. Explain that people have the right to refuse to answer any or all questions.
- DO emphasize that all information will remain confidential and that no one can be identified by his or her specific answers.
- DO make the interview situation as comfortable as possible. Act in a professional manner.
- DO inform people that you want their honest answers, even if their feelings are negative ones.
- DO allow plenty of time to complete the Protocol. Answers will be more accurate and useful if people do not feel hurried.
- DO inform participants in advance that some of the items are sensitive in nature. Briefly explain why you will be asking about potentially sensitive subjects.
- DO distribute referrals to professional and self-help organizations and services to all people participating.
- DO make it clear to the participants that any opinions expressed will not influence their access to services or assistance when administering the Protocol in a place where they might receive services.

- ➡ DO consider have a "debriefing" after the interview, when respondents can express their feelings, ask questions, and deal with any discomfort or upsetting feelings they may have had while completing the Protocol.
- ➡ DO follow up by sharing the results of the Protocol with respondents in summary form, so they can see that their opinions were valued and taken seriously.



Section Summary.

In this Section, we described how to administer the POP. We covered how to gather the materials before the interview and how to prepare the respondent for the interview. Directions to the interviewer were given, including how to read the questions, use response cards, and code answers. A list of "tips" was given to help make the interview process easier and the results more meaningful.

Section 3

AFTER THE INTERVIEW

Introduction.

In this final section, we discuss what happens after the interviews are conducted. This includes debriefing the respondents (or talking about how people feel after finishing the POP), "debriefing" yourself as the interviewer, and sharing the results with respondents later. In addition, this section suggests ways that your program might use the information you collect to help peers in a variety of ways.

Debriefing the Respondent after the Interview.

There are many benefits to having people discuss how they felt while completing the interview. This is especially true for people who have a negative reaction to one or more of the questions or sections. Be prepared to refer people to needed services or supports. These include hotlines, "warm-lines," drop-in centers, self-help groups, or services provided by professionals. People who are not receiving services at the time they complete the Protocol especially may need referrals. It would be helpful if you put together a list of such referrals, including national as well as local referrals. Resources can be listed on an index card or business card, both of which are easy for people to carry in a wallet or pocket for future reference should the need for support arise.

In the rare case that a person becomes extremely upset while answering questions, it is very important to assist him or her in getting help. This may mean contacting a counselor or physician if the person is receiving services, or a program equipped to provide emergency services, but only with the respondent's permission. Additionally, you may need to arrange for

transportation by contacting a friend or family member if the person appears to be too upset to safely reach the destination, be it a mental health agency or private home.

Debriefing Yourself after the Interview.

Administering the survey can be tiring, both physically and mentally. The respondent's experiences and emotions may be sad or upsetting. In some instances they may remind you of your own personal difficulties now or in the past. It may help to remember that you are gathering information to help your program be more useful for its members. Although the process of interviewing may be difficult, the end result will hopefully be a positive one.

Before conducting the Protocol, you should take time to consider what support you may need after the interview. If you feel down after the interview, you should talk to someone about these feelings. This might be a friend or family member or a peer or professional service provider. You might want to use one of the referral sources you provide to respondents. Of course, you should never talk to anyone about what was said in any interview in a way that could identify the respondent.

In addition, you might want to plan to do something relaxing right after finishing an especially difficult interview. This could be something by yourself or with others, such as reading, exercising, watching television, or going to a movie.

In the weeks or months that follow, you should not discuss, with the respondent, the information you were told as part of the interview, unless that person shows a desire to do so. All information must be kept completely confidential unless the person who was interviewed decides to make some of the information public.



Time Out!
*Take some time for emotional and physical rejuvenation
 after conducting interviews.*

Sharing your Results with Respondents.

Consider sharing the final results of your POP survey with the respondents. By results, we mean a summary of the information gathered after all interviewing has been done and the responses to questions have been totaled. In this way, all of the information is described in general, without identifying "who said what."

Doing so shows the participants:

- You took their participation seriously and value what they shared;
- You are using the results to educate others about the needs of peers;
- You hope to improve services or support for peers by applying what you've learned.

Sharing the findings “gives something back” to the people who have invested time and effort to complete the POP. Additionally, by increasing their knowledge of the needs of peers, you may encourage your respondents to initiate their own advocacy efforts. Keep in mind, however, that you should NEVER offer to share results with respondents unless you have every intention to do so. Follow through on any promises made to the participants. Also, if you administer the Protocol in a group setting, individual results NEVER should be shared to protect the participants' confidentiality. Instead, the overall findings or “themes” that emerged from the groups' responses can be discussed. Finally, all results should be presented in a format that is easy to understand. That means either explaining the findings in “layperson” terms, or preparing reader-friendly materials for the participants.



The K.I.S.S. Principle

The best way to be sure that people understand the information you are sharing is by using the K.I.S.S principle; that is, "**Keep It Short and Simple.**"

Using What You've Learned.

The POP was created to gather the kinds of information needed to evaluate the services delivered by and for peers with psychiatric disabilities. Use of the Protocol can assist the mental health and disability fields, and the peer empowerment movements, to evaluate what they're doing and present the findings to public funding authorities and health organizations. The information also can improve peer-run programs and enhance the support they give to peers. If the results of the survey show that there are needs that have not been met, this information can be used to help persuade policy makers and administrators to consider reforms that will benefit peers, including more funding for peer-run programs.

There are many potential uses for the POP data. The most obvious is to improve existing programs for peers by filling the gaps in services where people's special needs are not met. Another use for the information is to increase service providers' understanding of the needs of peers, especially the needs of under-served groups of peers, including those who are older, members of racial and ethnic minority groups, trauma survivors, and others.

Another use is for program evaluation efforts aimed at objective assessment of how well service recipients' needs are being met. Especially important to program enhancement is the ability to identify where peers feel they are being overserved, since reducing the program's efforts in these areas (following careful consideration and discussion) can allow time and money

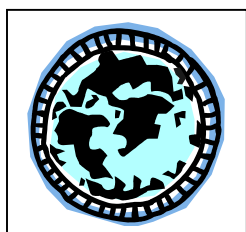
to be shifted to new services and supports without imposing undue burden on staff or other resources. POP survey results also can be used to plan in-service training focused on areas targeted by the Protocol's different domains.

Use the POP as a tool to:



- *Advocate for funding*
 - *Improve existing services*
 - *Strengthen clinical relationships*
 - *Evaluate the effectiveness of programs*
 - *Facilitate family understanding*
-

Because of its modular design, the Peer Outcomes Protocol meets a variety of purposes. You can administer single sections, selected multiple sections, or the entire Protocol. Depending on time and resources, items can be omitted if it is felt that they are not necessary. The only claims asserted on behalf of the Protocol is that it covers areas of concern thought by peers, providers, advocates, researchers, and family members to be especially relevant to people with psychiatric disabilities.



Use the POP in these Real World Settings:

Self-help organizations
Consumer-run employment programs
Mental health advocacy programs

Consumer-run drop in
Peer support groups
Consumer-operated recovery programs



Section Summary.

In this section, we presented various uses for the Peer Outcomes Protocol in a variety of real-world settings. Potential users of the survey results were identified, along with ways to share the results. The convenient, flexible nature of the Protocol was highlighted, with an emphasis on how it could be tailored to fit multiple purposes. We hope that dissemination of this Peer Outcomes Protocol and Administrative Manual will encourage others to increase their appreciation of peer support, self-help, and peer-operated services.