



DIY LIVED EXPERIENCE RESEARCH RESOURCE MANUAL FOR PEER WORKERS

Manual 5: Accessing Physical Health Care



STELLER: Supporting the Translation into Everyday Life of Lived Experience Research



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Contents

INTRODUCTION 3

 About the resource 3

 Accessing the full article..... 3

ARTICLE SUMMARY 4

 Context for the study 4

 Methods 4

 Research Findings..... 4

VALUED FEATURES OF THE RESOURCE 7

PRODUCTION INSTRUCTIONS 8

 Option 1..... 8

 Option 2..... 8

GUIDELINES FOR USE 9

 Possible discussion questions: 10

RELECTION FOR PEER WORKERS..... 11

ARE YOU READY? CHECKLIST 12



INTRODUCTION

This manual is produced by STELLER and is one of a set of manuals accompanying our DIY suite of lived-experience research resources. Manual 5 relates to a set of cards: Accessing Physical Health Care. It assumes that you have already read Manual 1: Getting started. If you have not read that manual already, please do so now, as it contains important contextual information.

The manual contains information about the original research on which the Accessing Physical Health Care resource was based – it is important for you to understand the research in more detail to answer questions and provide the people you work with additional insight. Reflection questions encourage you to think about the application of the resource to your own life to assist you in using the resource with others. This manual also tells you how to produce the resource and gives tips and considerations for using it with people.

If you have any questions or would like to provide feedback on this resource, you can contact Anne Honey at anne.honey@sydney.edu.au.

About the resource

- Ewart, S., Bocking, J., Happell, B., Platania-Phung, C., & Stanton, R. (2016). Mental health consumer experiences and strategies when seeking physical health care: A focus group study. *Global Qualitative Nursing Research*, 3, 1-10.
<https://doi.org/10.1177/2333393616631679>

The researchers conducted focus groups with 31 people living with mental health issues to find out about their experiences using health services for their physical health needs, as this group often do not get the same level of physical health care that other people do. The STELLER research project created a set of cards called 'Accessing Physical Health Care' based on these findings. There are 26 cards, with a colourful design on the back, similar in size to a normal deck of cards. The front of the cards are colour matched in pairs to allow them to be used to play a memory game. The first four cards include an introduction, overview of the study and suggested use of the resource. The remainder of the cards are separated into eleven themes (two cards per theme), with unique colours representing each theme. One card in each pair provides a description of the theme and the other includes direct quotes from participant in the research. Reflective questions are also sometimes included. For example, the "taking time" pair includes: "People said that it was important to allow enough time in an appointment to fully deal with physical concerns"; and "One person said that if he was feeling hurried or rushed, he would say: 'Well hang on a minute. I need help with this. Can you refer me to these other services?'. What else might you do or say to make sure you get the time you need with a health professional?".

Accessing the full article

The full article is available free of charge at:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5342294>



ARTICLE SUMMARY

Australian lived-experience researchers did focus groups with 31 consumers to find out about their experiences in using health services for their physical health needs.

Context for the study

People who live with mental health challenges have more physical health problems than other Australians, and have a lower life expectancy. There may be different reasons for this, including impacts of medication, but one important reason, which often goes unacknowledged, is that people living with mental illness often do not get the same level of physical health care that other people do.

The experiences of participants in this study provide ideas for other people about how to get their physical health needs met.

Methods

The researchers used an exploratory qualitative design to get the diverse perspectives of participants. The 31 participants were members of the ACT Mental Health Consumers Network. Focus groups, with 7-9 participants each were conducted, and lasted between 90 to 150 minutes each. They were conducted by a lived-experience researcher and another academic researcher together. Participants talked about their physical health and their experiences of “seeking, using, and forming relationships” with physical health services. Data were analysed using Thematic Analysis.

Research Findings

Consumers described how having a diagnosis of mental illness was a major barrier to communicating with health professionals about their physical issues. Many felt that when health professionals knew about the mental illness, they focused on assessing and treating that and dismissed the physical problems.

“[Rather than] ‘we need to get you on a diet... we need to get you on that plan’... it’s first ‘how’s your mental health? Are you okay? Stick to these drugs, you’ll be fine.’”

Sometimes health professionals also did not take notice of what the consumer said that they needed, thinking that they knew better.

“I’m here because I have made an informed choice, involving self-determination that I know will benefit both my mental and physical health and you’ve just told me that it won’t. That’s so disheartening. That’s so disempowering.”

While consumers respected the knowledge of health professionals, they thought that they were the experts on themselves and this should be acknowledged by health professionals.



“I feel like there needs to be a shift in power. So instead of me going to the expert and being told what to do, and me thinking that’s going to cure myself. I want to be – I know myself better than anyone does.”

Some people felt that they could not get attention for their physical concerns until there was a crisis:

“It works backwards. You go to the crisis, and then you get the help. And you don’t get the help if you present without a crisis.”

Bad experiences with health providers made consumers feel hopeless, with “nowhere to turn to” and discouraged them from seeking help for physical problems. Not getting the help that they needed was bad for both their physical and mental health.

This was not the case for everyone, however, and finding a health provider who would listen and address physical concerns was seen as critical. When consumers found such a person, they felt very lucky and saw the relationship as precious.

“they need to believe the client. You’re not making things up and they can check for themselves and see, you know. If I find a good doctor, I hang onto them.”

Consumers sometimes had to be persistent to find the right health care provider.

In the future, consumers hoped that more health professionals would change their attitudes and provide better physical health services to mental health consumers. However, in the meantime they had developed some strategies to help them get the care they needed.

Some talked about preparing for the health care interaction by finding out information beforehand:

I actually google symptoms. So I have the right language to use when with the doctor. That’s one of the strategies that I use.

Others felt that it was important to not allow the doctor to rush them to fit in the “10 minute window”:

It’s taken me a long time to have the courage to say, ‘Well hang on a minute. I need help with this. Can you refer me to these other services?’... and say ‘Well, this is what’s helping, and this is what’s not helping’.

Some felt that they got better attention for their physical problems if they “just don’t tell them” about certain aspects of their mental health.

Consumers regularly talked about the importance of questioning health professionals and not taking their word as “gospel”. They also felt that they needed to be assertive and not accept bad treatment.

Well doctors aren’t gods and you should question them and if you find a good doctor, hang on to them, and the other ones I think you should report them... Yeah, I reported them, there was an investigation.

I had to learn how to choose to see another doctor.



While consumers did not often discuss the issue of physical health care providers with each other, when they did this was useful. Other consumers were a good resource for finding out names of good, consumer-friendly health care providers in the area.

In a related article, participants also thought that there was great potential for involving other people with lived experience, especially peer workers, in physical health activities. The ways that peer workers were thought to be able to help were:

- Giving health promotion information
- Advocating with health professionals
- Helping with motivation to do healthy activities
- Accompanying the person to the gym or a pool or for a walk
- Social support and empathy
- Explaining how to make complaints about bad experiences

If you're particularly interested in this topics, two related lived experience articles are:

Bocking, J., Ewart, S. B., Happell, B., Platania-Phung, C., Stanton, R., & Scholz, B. (2018). "Here if you need me": exploring peer support to enhance access to physical health care. *Journal of mental health (Abingdon, England)*, 27(4), 329. <https://doi.org/10.1080/09638237.2017.1385741>

Happell, B., Ewart, S. B., Bocking, J., Platania-Phung, C., & Stanton, R. (2016). "That red flag on your file": misinterpreting physical symptoms as mental illness. *Journal of Clinical Nursing*, 25(19-20), 2933–2942. <https://doi.org/10.1111/jocn.13355>



VALUED FEATURES OF THE RESOURCE

The Accessing Physical Health Care resource was found to be helpful by 87% the participants in our study who viewed it and 67% rated it as very interesting or extremely interesting. Around 87% of participants saw it as resulting in a small or big improvement in “your ability to care for yourself and your mental health”.

The most common things that study participants said they liked or valued about this resource were:

- The information was practically helpful.
- It was straightforward and easy to use.
- It was creative and resonated with people’s experiences.

Here are a few things our participants said:

It was really useful because in the early days I tried to get help for my physical body but I didn't know where to start, how to go about it. But those cards provide all of that. With them alone you can make up a bit of a plan to sort out your physical issues.

I have developed a wide range of physical health issues since my mental health diagnosis. This is, therefore, an issue close to my heart. The cards are a novel way to convey information. The information is pertinent, accurate and conveyed clearly.

[I liked] the card that says you have choices [and about] seeing the whole person. I live with my sister so I showed them to her. She was quite impressed with them as well.

The physical health resource was really good for me as well. Because it talks a lot about [how] you can change your doctor [and] when you go to the doctor, make sure you write things... It's practical with, what can you do about your physical health, what do you do when you go to the doctor, the fact that you can change as well, or prepare yourself. And there was some good quotes.

It made you think. And if you do it again it's like another thought...It was done easy, it was no gibble gabble crap... it was straight to the point.

And from one of our peer workers:

A lot of my consumers were like ... they weren't just like, "This is amazing." But they were like, "Oh, that's what I want to do." Or, "That's what I would do." There was a very good response with the actual content of the cards... also, I could see that it could give them an opportunity if they couldn't step up or couldn't talk to the doctors about things, be like, "Oh, there's this card that says I can."



PRODUCTION INSTRUCTIONS

We have provided 2 sets of instructions. The first is the high-quality version, while the second is a less costly and more 'in house' option. In both, the resource consists of 26 cards measuring 80x120mm. Each has writing on one side and a colourful design on the back. The PDF file provided is set up to be used for double sided printing, with 4 cards per A4 sheet. The dotted grey lines show where to cut around each card.

Option 1

For high quality kits, please follow these instructions when printing the resource from the accompanying PDF file. This version should be used as a take home version where budget allows, but definitely for kits to be used by peer workers (or other support workers) with consumers or kept in places like wards or waiting rooms for use by/with multiple people.

- Cards should be printed in colour, double sided on 300gsm gloss cardboard.
- This will need to be done by a commercial printer. This cost us about \$11 per set for a run of 25, so it is likely to be more expensive for a smaller number. You can ask the printer to cut them or guillotine them yourself.
- They should be kept in a clear plastic envelope, available at very low cost at many bargain shops.



Option 2

For less costly 'in house' production of kits, the cards could be printed in the office, preferably on cardboard; light cardboard can be used in most office quality printers. This version would only be suitable for handing out to clients when a higher quality option is not feasible. A light-weight version would be particularly difficult to use in a game format.



GUIDELINES FOR USE

As with all the resources, how you use it with your client will depend on the client. Suggestions are below.

The pack of cards includes coloured cards with key quotes and findings from the research, as well as several white cards that contain background information about the research and instructions on how to use the cards to play a memory (matching) game. Pairs of cards with the same colour scheme are a “match”.

- Use the white cards to provide the client with a brief background on the topic of physical health.
- Discuss a couple of cards with the client as examples. Then explain various ways that the cards could be used – as a memory game, going through the cards by themselves, going through them together with the peer worker etc.
- Explain that the matching colour pairs have related text – usually there is a point from the research on one of them and a quote from a research participant about that same topic on the other – so they should be read together.
- Ask clients how they want to engage with the cards. Some might enjoy playing the memory game and this could be done with you, the peer worker, or as a small group activity, with discussion around the content of the cards when a match is achieved.

Please consider the following issues when deciding how to use the Accessing Physical Health Care cards with clients.

- Only some people in our study were interested in using the cards to play the game – this is only one option.
- The resource reflects what participants found helpful in accessing physical health care. When using the resources with clients, bringing the conversation back to the practical strategies they can use in their own situation is important.
- Using the resource in a group, to stimulate discussion around strategies for getting good physical health care or share community resources and recommendations may well be beneficial.
- A couple of people thought that the resources could be more detailed and specific. Not a great deal more detail around strategies is provided in the original article, which discusses the strategies mainly in the context of barriers experienced. So discussion around specific local resources and knowledge you have gained from other consumers you have worked with may be warranted for these kinds of people.
- One of our peer workers reported that participants sometimes needed extra explanation to understand how to play a game with the cards.
- Because physical health care is such an issue, and some people may have had negative experiences in seeking physical health care or “trauma around seeing doctors”, it is particularly important to check in on how people are feeling after using the resource. One participant found the information “a bit idealistic” in the context of current access to good physical health care. However, if this is an issue for people, opening this discussion will allow the peer worker to support them in addressing the problems they are encountering.



Possible discussion questions:

These are some suggestions for questions you might ask to generate discussion and help the person reflect on the resource.

Prior to giving the resource:

- How confident are you in getting good treatment when you need help with your physical health? Why?
- So you have any concerns about your physical health at the moment?

Afterward:

- What stands out for you about the Accessing Physical Health Care set of cards?
- Which quotes or ideas do you most identify with? Why?
- Are there ideas in this resource that you don't agree with, or that don't fit in with your experience? How?
- Are there any ideas in the cards that you think you could use in your own life? How?
- Do you have any different strategies to make sure you get the best physical health care? What are they?



REFLECTION FOR PEER WORKERS

As we outlined in Manual 1, it is important that prior to introducing a STELLER resource to someone else that you have used it yourself. Use the reflection questions below to become more familiar with each resource.

<p>1. What surprised you about the research findings presented on the Accessing Physical Health Care cards?</p>	
<p>2. How does this information inform and/or impact your own recovery processes?</p>	
<p>3. After using the Accessing Physical Health Care resource, what might you consider differently in your own recovery?</p>	
<p>4. List the points you would make when introducing this STELLER resource to others? <i>(be sure to share your own experiences of using this resource)</i></p>	



ARE YOU READY? CHECKLIST

I've read and understood Manual 1 – Introduction to STELLER	<input type="checkbox"/>
I feel confident to explain lived-experience research and the background to the resources	<input type="checkbox"/>
I've read the article summary in this manual and gone through the cards	<input type="checkbox"/>
I've produced the resource in accordance with the instructions	<input type="checkbox"/>
I've used the resource myself (including playing the game) and reflected on the questions for peer workers in this manual	<input type="checkbox"/>
I've read the guidelines for use in this manual and feel confident of how to introduce the resource	<input type="checkbox"/>
I know what reflection questions I want to ask to start discussion	<input type="checkbox"/>
I have a plan for following up with the person/ checking in with them afterward about the resource.	<input type="checkbox"/>