



LETTER OF INFORMATION / CONSENT

Research Blog for Psychiatric Users/Survivors to Review and Discuss Literature and Other Media

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Purpose of the Study: You are invited to take part in this research blog (on-line journal). In the blog, people who self-identify as having had experience of the mental health system can review and discuss media which deals with themes of mental illness (sometimes called “madness”) and/or psychiatric treatment. You can review any kind of creative media such as novels, memoirs, poetry, plays, films, visual art, music, advertising, video games, television shows and comic books, as long as they fit the theme.

You may define yourself as a psychiatric survivor, psychiatric user/consumer, (ex-)patient or mad person or you may choose not to use a label. You may be any gender and can live anywhere in the world. **You must be over the age of 18.** You must be able to read and write in English. There is no set number of participants. There is no payment for taking part in this study.

In this study, I am hoping to find out if and how people who have had experience of the mental health system interpret media differently based on having had that experience. I am also interested to see whether people find reading and writing about materials dealing with themes of mental illness/madness and/or psychiatric treatment in an interactive setting personally, socially and/or politically useful or not.

I will be exploring the media interpretations and perspectives of people who've had experience of the mental health system in a chapter of my thesis. The chapter explores what it means to read from a mad perspective. It also looks at the ways in which mad people empower themselves by creating networks through which to discuss ideas about, and practices based in, experiences of madness/mental illness. My thesis might describe or quote research blog posts and conversations. I may also use content from the blog in other

publications or presentations related to my thesis. Your real name or other information that might personally identify you will not be used in my thesis or in other publications or presentations.

What will happen during the study?

- After agreeing to take part in the study by reading this letter of information, and checking off the relevant boxes on the consent form, you will be asked to set up a user account on the blog website wordpress.com, using a pseudonym (made-up name). You can choose your own pseudonym. To protect your own identity and confidentiality, **you cannot use your real name in the research blog**. Please choose a pseudonym which other people would not easily associate with you. If you are already a wordpress.com user, you will have to create a new account using a different name for the purposes of the study. It is very easy to sign up for an account. You just need to visit <https://en.wordpress.com/signup/?user=1> and pick a username and password.

- Once you are signed up as a wordpress.com user, let me know your username, and I will add you as an author to the research blog. As an author, you will be able to post media reviews, comment on other authors' reviews, and respond to other authors' comments. You may also add, edit or delete any of your entries or comments. I will serve as the moderator of this blog. I will perform the usual functions of moderators, which are to ensure that everyone follows the blog's terms of use, which relate to respectful participation.

- There are tutorials on wordpress.com which show you how to post entries and comments. I will be available by email if you need help figuring out the site.

- **You are invited to post reviews of media of your choosing, and talk in particular about aspects of that media which represent or relate to madness/mental illness and/or the mental health system.** You are encouraged to talk about any of the following things:

- what you liked or didn't like about the media
- how the media made/makes you feel
- how you think it represented madness/mental illness
- what message you think the audience will get from it
- how it relates to your own experiences or identity
- what political implications the media has (do you think it will affect mental health treatment or government policies related to mental health?)
- practical impact the media may have had on your life (did it change any of your thoughts, ideas, routines, coping methods?)

- You do not have to talk about all of these things in each review. **You can write as much or as little as you want.**

- Reviews do not have to be written in a formal tone, or using perfect grammar or spelling; however, they need to be readable to others, so please try to write in full sentences, use plain language, and read over your entries at least once before posting them.

- You should also try to post information about where the media you are discussing can be found (web address, author and publisher for print sources such as books, date and director for films, gallery name for pieces of art etc.). This will help other users can find that resource if they are interested in it.

- Users will be able to comment on each other's entries, as well as respond to comments left by others. **Please be considerate of others when you are posting comments.** Think of how the comment would make you feel if someone made that comment on your entry.
- I will moderate the blog. Although it is okay to disagree with others' opinions on the blog, comments or reviews which are abusive, threatening or personally insulting to other users are not allowed. The blog is meant to be a supportive and inclusive environment. Inappropriate posts will be removed, and the person responsible will be told not to post similar things in future. If a user posts inappropriate reviews or comments a second time, he/she will no longer be allowed access to the blog.
- As a psychiatric survivor myself, and someone interested in media representations of madness/mental illness and the mental health system, I will also be a user of the blog. Like any other user, I will post reviews of media, which you are welcome to comment on and critique.
- When you are reviewing media, your own experiences may come to mind. You are allowed to share life experiences or discuss aspects of your identity that relate the material you are reviewing. However, **you are not required to share any personal experiences or information on the blog. My primary purpose is to learn about your opinions about depictions of madness/mental illness and psychiatric treatment.** While there may be a connection to your own life, writing about your experiences might reveal things about yourself which you might not want other people to know. You might also be able to be identified by others if you choose to write about your experiences.
- I will send out a monthly newsletter for the research blog just to check in with and thank everyone taking part. The newsletter will list the contributions to the blog that month. I may also include links to news articles, book reviews etc. which might be of interest to participants.
- I will be collecting data from the research blog for one year. You will be able to post in the blog beginning November 1st, 2011. Although the blog will remain open to users after November 1st, 2012, I will no longer be collecting any data from it for research purposes. A summary of the blog findings will be available by December 1st, 2012. If you are interested in receiving this summary, please check off the box in the consent form below. Any updates as to the timing of the blog project will be communicated in the monthly newsletter.

Are there any risks to doing this study?

- The risks involved in participating in this study are minimal.
- As someone with experience of the mental health system, you may find that writing and reading about depictions of madness/mental illness and/or mental health treatment may bring up strong feelings and/or memories which may be upsetting.
- You are not obligated to comment on any material which you find upsetting.
- If you do want to share how particular media or reviews have made you/are making you feel, the blog is a safe space in which to do so.
- If you do not feel comfortable sharing your feelings in the blog, or you need to talk to someone in person, there will be a list of crisis and support services available to you on the blog (that list is also included at the end of this letter).

Potential Benefits

- You can have discussions with other people who have had some similar experiences on the blog. The research blog will be an on-line space for social interaction, support, and fun.
- The blog may be a useful resource. You might find out about media relating to madness/mental illness or the mental health system which you might not find otherwise.
- The blog will be a space for learning, sharing interesting ideas, and possibly debate.
- Reading and discussing media that deals with the theme of madness/mental illness and the mental health system may help you work through some of your experiences. The materials, and your interactions with other members, might also give you new ideas and/or strategies.
- The material you contribute to the blog will help me to understand and talk about the perspectives people who have had experience of the mental health system bring to media representations of that system. It might also help other researchers in future. The opinions you share in the blog will give a better understanding of experiences which might be described as mad or mentally ill from the perspectives of people who have experienced them.

Confidentiality

- I will not use your name or any information that would allow you to be identified on the blog, or in my thesis. You will be using a pseudonym on the blog. Only I will have your real name and email address. I do not require any of your other personal information. I will keep your name and email address password protected in my professional email account only as long as I am doing this research.
- The blog will be set to private, which means that it will only be accessible by me and other blog authors. It will not be publicly searchable on Google or other search engines.
- I will take on the role of researcher only in the context of the blog. The only information I will be using for research purposes is that which you contribute to the blog using your pseudonym. Contributions you make to other blogs, listservs, in-person meetings etc. in which I participate will not be included and will remain confidential.
- While I will take every precaution to ensure your confidentiality, I cannot guarantee that you will remain absolutely anonymous for the following reasons:
 - 1) Since participants will be drawn from the fairly small psychiatric user/consumer/survivor/ex-patient community online, it is likely that many blog users may already know each other on-line and/or in person. They might be able to identify one another based on that knowledge. We are often identifiable through the way that we write, the references we make, or the stories we tell. To protect the confidentiality of your fellow users, please do not reveal their identity or supposed identity. Please also be careful not to reveal personal or confidential information about other people who are not blog participants within your blog entries.

2) Even in a private online environment, there is always the risk of intrusion by outsiders, such as hackers, and therefore the possibility of being identified.

b) Legally Required Disclosure

Researchers are generally required to reveal certain information if it is required by law (ie. if children are being abused; if they know of a public health risk, etc). Although I will protect your privacy as outlined above, if the law requires it, I will have to provide the personal information requested.

If you are currently considering doing harm to yourself and/or others and you say so in the research blog, I am required to contact a crisis centre in your area on your behalf. This does not apply to discussions of past feelings or actions. If you are in crisis, or are feeling suicidal, please talk to a friend, family member, peer support worker, counsellor, social worker, family doctor or religious leader. Or you can access crisis, counselling or peer-support services in your area (see listing of these at the end of this letter).

Participation and Withdrawal: Your participation in this study is voluntary. **If you decide to take part in the blog, you can decide to withdraw (stop) at any time, even after signing the consent form, or part-way through the study.** You do not have to explain your reason for withdrawing. You may also choose to limit your participation instead of withdrawing. There will be no consequences to participating less or withdrawing. If you would like to withdraw from the blog project permanently, you simply need to notify me by email. I will remove you as a blog author within 48 hours. If you choose to withdraw, you will be asked if you would like to delete your data before you are removed as an author. If something you wrote in the research blog has already been used by me in a publication or presentation, I will not be able to omit it from my work. Any other data you choose to leave in the research blog may be discussed in my thesis or in other publications and presentations after your withdrawal.

Questions about the Study: If you have questions, need more information about the study itself, or are interested in learning more about my thesis project, please contact me at any of the following:

E-MAIL: wolfram@mcmaster.ca

SNAIL MAIL: c/o Department of English and Cultural Studies,

Chester New Hall 321, McMaster University,
1280 Main Street West, Hamilton, Ontario, Canada, L8S 4L9

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

c/o Research Office for Administrative Development and Support
E-MAIL: ethicsoffice@mcmaster.ca
PHONE: 905-535-9140 ex. 23142

CONSENT

Read each statement below. Check off each box on the left with an 'x' to show that you understand and agree to each statement.

- I have read the information presented in the information letter about a study being conducted by PhebeAnn Wolframe of McMaster University.
- I have had a chance to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw (stop) at any time.
- I have had experience of the mental health system and I am over the age of 18.
- I have been given a copy of this form. I agree to participate in the study.

Read each statement below and answer yes or no by putting your answer in **bold**:

1. I agree to contribute to the research blog by posting media reviews and/or commenting on other users' reviews using a pseudonym. **Yes** **No**

2. I understand that my blog contributions may be quoted in PhebeAnn Wolframe's PhD thesis using a pseudonym. No personally identifying information will be used in her thesis or related publications or presentations.

Yes **No**

3. I would like to receive a summary of the research blog findings following the completion of the blog project. **Yes** **No**

If yes, where would you like the summary sent:

Email address:

4. I agree to be contacted about future research and I understand that I can always decline the request for any reason. **Yes** **No**

Name of Participant (typed):

City and Country in which you live (please do not provide your full address):

Date:

Please complete the following steps:

- 1) fill out this form using your word processor;
- 2) write an email stating that you have read and understand the terms of the study, *Research Blog for Psychiatric Survivors to Review and Discuss Media*, and that you consent to participate in it;
- 3) attach your filled-out consent form to the email;
- 4) send the email to me at: <wolfram@mcmaster.ca>.

Crisis and Counselling Resources (this list will also be posted on the blog's main page)

Peer Support Services in the Hamilton Area

- Mental Health Rights Coalition
<http://www.mentalhealthrights.ca/>
905-545-2525
Peer-run drop-in centre located at 20 Jackson St. W., Suite 206A. See webpage for hours.
Peer-counselling program available.
- Hamilton Mood Menders Support Group
(A peer-support group affiliated with Mood Disorders Association of Ontario)
Voicemail: (905) 521-0090 ext. 234

Crisis Services in the Hamilton Area

- Hamilton Suicide Prevention Line **(905) 522-1477**
- Burlington Crisis Response Team **(905) 631-1939**
- COAST CRISIS LINE (Crisis Outreach and Support Team)
The COAST team provides assessment, treatment, support and referral for people experiencing crisis.
(905) 972-8338 or Toll Free **1-877-825-9011**

Peer Support Services in Toronto

- Sound Times Peer Support Services
<http://www.soundtimes.com/contact.html>
Drop-in centre located at 280 Parliament Street. See webpage for hours.
- Mad Students' Society
Mad Students Society (MSS) is an organization run by and for students. MSS was created to provide peer support, advocacy and self-empowerment for students experiencing mental health issues.
They have twice monthly meetings and run an email listerv.
<http://www.madstudentsociety.com/meetings.html>

- There are several Toronto peer support groups affiliated with the Mood Disorders Association of Ontario. Go to <http://www.mooddorders.ca/peer-support-groups-across-ontario> and click on "Toronto" for a listing.

- WHAT NEXT! Peer Support Program
<http://www.whatnextdropin.ca/>

What Next! Peer Support Drop-in Centre is a membership-driven meeting place where people recovering from mental health or mental health and addiction issues can share with others and gain social and emotional support.

Located at 3701 Chesswood Drive, Suite 208. See webpage for hours.

Crisis Services in Toronto

- Distress Centres of Toronto: **(416) 408-4357**

Listings of Additional Support and Crisis Services (Local & International):

- Distress Centres of Ontario (lists hotlines and other crisis services in Ontario):
<http://www.dcontario.org/centres.html>

- Self Help Resource Centre - listing of self-help services across Ontario:
<http://www.selfhelp.on.ca/>

- The Ontario Peer Development Initiative - listing of consumer/survivor peer services across Ontario:

<http://opdi.org/index.php/ourmembers/>

1-866-681-6661

- The Canadian Association for Suicide Prevention

<http://www.casp-acps.ca/crisiscentres.asp>

Has listings of suicide support groups and crisis centres across Canada.

- The American Association of Suicidology: (USA)

Crisis Line:

1-800-273-TALK (8255)

<http://www.suicidology.org/web/guest/home>

Has listings of suicide support groups and crisis centres across the United States.

- Samaritans: (UK)

08457 90 90 90

<http://www.samaritans.org/>

Offers 24-hour support for people in distress or despair, including those feeling suicidal. They have branches all over the United Kingdom and Ireland and most branches are able to offer services via telephone, email, letter and face to face.

- Befrienders (International)

Has a searchable listing of crisis hotlines and centres internationally:

<http://www.befrienders.org/support/helplines.asp>

- MindFreedom International:

Directory of Mental Health Alternatives Searchable Database (Canada, USA, UK)

<http://www.mindfreedom.org/mfdb/mfdb-search-form>

- Intervoice: The International Community for Hearing Voices

Online discussion forum; online guide for learning to cope with voices; online directory of international peer support groups for voice-hearers.

<http://www.intervoiceonline.org/support-recovery/hearing-voices-groups>