DBSA Consumer and Family Survey Center

Consumer Attitudes Towards Participation in Clinical Research
Spring 2010
Consumers Attitudes Towards Clinical Research

• Background – DBSA Consumer and Family Survey Center
  – Quarterly Web Based Survey: www.dbsalliance.org
  – Subject Areas
    • Demographics/background
    • Participation consideration
    • Reasons to not participate
    • Reasons to participate
    • DNA and research
Part 1: Demographics/Background

- Sample Size: 424 (open web based participation)
- Respondents: 81% Female; 89% Patient, 10% Family/Friend
- Diagnosis: 58% Bipolar, 30% Depression, 5% None
- Education: 37% Completed High School, 36% Completed College, 22% Advanced degree
- Age Range: (14 – 72 Years of age)
  
  - <21 (1%)
  - 21 – 29 (13%)
  - 30 – 45 (39%)
  - 46- 65 (44%)
  - >65 (1%)
Age Range

- < 21 Years (1%)
- 21 - 29 Years (13%)
- 30 - 45 Years (39%)
- 46 - 65 Years (44%)
- > 65 Years (1%)
- Unknown (1%)
Education

- Completed High School (37%)
- Completed College (36%)
- Advanced Degree (22%)
- < High School (3%)
- Completed College (36%)
- Advanced Degree (22%)
- Unknown (1%)
Have you ever heard of clinical research?

- Yes (85%)
- No (8%)
- Not Sure (5%)
- Unknown (2%)
Have you ever participated in a clinical research study, either for mental health or other health conditions?

- No (75%)
- Yes (20%)
- Not Sure (3%)
- Unknown (2%)
Have you ever been referred, or recommended, to participate in a clinical research study?

- Yes: 19%
- No: 74%
- Not Sure: 5%
- Unknown: 2%
Part 2: Participation Consideration

What information would be important for you to have when thinking about participating in a clinical research study?
What to expect from participating in a clinical research study, including the advantages and disadvantages

Very Important (86%)

Somewhat Important (10%)

Not Very Important (0.7%)

Unknown (3%)

Very/Somewhat Important = 96%
Brochures that clearly explain the research study

Very/Somewhat Important = 94%
Who is conducting the study (e.g., a medical school, a team of researchers, etc.)

Very/Somewhat Important = 94%
Who is paying for the study

Very Important (57%)
Somewhat Important (30%)
Not Very Important (9%)
Not Important (2%)
Unknown (2%)

Very/Somewhat Important = 87%
Whether mental health consumers are part of the research team

- Very Important (47%)
- Somewhat Important (33%)
- Not Very Important (12%)
- Not Important (4%)
- Unknown (4%)

Very/Somewhat Important = 80%
What other professionals who are not conducting the study say about it

Very Important (31%)
Somewhat Important (45%)
Not Very Important (17%)
Not Important (3%)
Unknown (4%)

Very/Somewhat Important = 76%
What other mental health consumers say about the study

Very Important (36%)

Somewhat Important (43%)

Not Very Important (13%)

Not Important (4%)

Unknown (4%)

Very/Somewhat Important = 79%
A recommendation by a provider who's treating you

Very Important (46%)
Somewhat Important (34%)
Not Very Important (12%)
Not Important (4%)
Unknown (4%)

Very/Somewhat Important = 80%
What the possible risks are

Very Important (90%)  
Somewhat Important (5%)  
Not Very Important (1%)  
Not Important (0.2%)  
Unknown (3%)

Very/Somewhat Important = 95%
Your right to withdraw from the research study

Very/Somewhat Important = 94%
Whether the study's results will be sent to you

Very Important (62%)

Somewhat Important (29%)

Not Very Important (5%)

Not Important (1%)

Unknown (3%)

Very/Somewhat Important = 91%
Part 3: Participation

• Would you be more or less likely to participate in a study that:
Was run by your clinician/provider

Very/Somewhat Likely to Participate = 78%
Was endorsed by your clinician/provider

- Very Likely to Participate (54%)
- Somewhat Likely to Participate (29%)
- Not sure (11%)
- Somewhat Unlikely to Participate (0.7%)
- Very Unlikely to Participate (1%)
- Unknown (4%)

Very/Somewhat Likely to Participate = 83%
Was testing a new medication(s) for your condition

Very/Somewhat Likely to Participate = 62%

- Very likely to Participate (28%)
- Somewhat Likely to Participate (34%)
- Not Sure (24%)
- Unlikely to Participate (7%)
- Very Unlikely to Participate (4%)
- Unknown (3%)
Was testing a new talk therapy for your condition

Very/Somewhat Likely to Participate = 87%
Required you to Participate in Medical Tests

Very Likely (33%)
Somewhat Likely (39%)
Not Sure (20%)

Very/Likely to Participate = 72%
Make information from your medical records available for research on your conditions

Very/Likely to Participate (39%)  
Somewhat Likely to Participate (29%)  
Not Sure (19%)  
Unlikely to Participate (5%)  
Very Unlikely to Participate (4%)  
Unknown (3%)

Very/Somewhat Likely to Participate = 68%
Required you to change your current course of treatment

Very/Somewhat Likely to Participate = 40%

- Very Likely to Participate (15%)
- Somewhat Likely to Participate (25%)
- Not Sure (36%)
- Unlikely to Participate (10%)
- Very Unlikely to Participate (9%)
- Unknown (4%)
Required you to provide tissue or gene samples for long-term comparison and analysis of treatment responses

Very/Somewhat Likely to Participate = 70%
Offered some form of compensation (monetary gift card)

Very Likely (44%)
Somewhat Likely (32%)
Not Sure (14%)
Unlikely to Participate (1%)
Very Unlikely to Participate (1%)
Unknown (8%)

Very/Somewhat Likely to Participate = 76%
• Part 4: Reasons to Not Participate
Below are some reasons why people choose not to participate in research studies. Please state how these concerns would influence your decision to participate in a study.
It would be too inconvenient, and I don’t have time

Strongly Agree/Agree = 31%
I have concerns about whether the researchers would be honest about the risks and procedures

Strongly Agree (22%)
Agree (31%)
Not Sure (17%)
Disagree (22%)
Strongly Disagree (5%)
Unknown (2%)

Strongly Agree/Agree = 53%
I don’t want to be “experimented” on

- Strongly Agree (10%)
- Agree (14%)
- Not Sure (21%)
- Disagree (37%)
- Strongly Disagree (14%)
- Unknown (4%)

Strongly Agree/Agree = 24%
I am afraid I’ll have to change medicines or treatment

Strongly Agree (17%)
Agree (27%)
Not Sure (27%)
Disagree (17%)
Strongly Disagree (7%)
Unknown (5%)

Strongly Agree/Agree = 44%
I am worried that it might affect my insurance coverage

Strongly Agree (14%)
Agree (16%)
Not Sure (25%)
Disagree (22%)
Strongly Disagree (9%)
Unknown (13%)

Strongly Agree/Agree = 30%
I am worried about Confidentiality

Strongly Agree (17%)
Agree (23%)
Not Sure (12%)
Disagree (31%)
Strongly Disagree (13%)
Unknown (4%)

Strongly Agree/Agree = 40%
I don’t know where to find information about research studies that I could participate in

Strongly Agree (30%)
Agree (34%)
Not Sure (12%)
Disagree (15%)
Strongly Disagree (5%)
Unknown (4%)

Strongly Agree/Agree = 64%
Part 5 – Reasons to Participate

• Below are some reasons why people choose to participate in research studies. Please indicate how these reasons would influence your decision to participate in a study.
I would like to help others or myself in the long run

Strongly Agree (76%)
Agree (21%)

Strongly Agree/Agree = 97%
I would like to improve the quality of my care

Strongly Agree (73%)
Agree (21%)
Not Sure (1%)
Disagree (.7%)
Strongly Disagree (.2%)
Unknown (4%)

Strongly Agree/Agree = 94%
I would like to earn money or other rewards

Strongly Agree (23%)
Agree (30%)
Not Sure (16%)
Disagree (17%)
Strongly Disagree (5%)
Unknown (8%)

Strongly Agree/ Agree = 53%
I feel pressured by my clinician, family, or friends to participate

- Strongly Disagree (37%)
- Disagree (41%)
- Not Sure (8%)
- Disagree (41%)
- Strongly Disagree (37%)
- Agree (1%)
- Strongly Agree (3%)
- Unknown (9%)

Strongly Agree/Agree = 4%
I think it would be interesting

Strongly Agree (46%)
Agree (38%)
Not Sure (7%)
Disagree (3%)
Strongly Disagree (2%)
Unknown (3%)

Strongly Agree/Agree = 84%
Part 6 DNA and Research

• In order to study mood disorders, DNA samples are needed from large numbers of people. This means that the researchers who collect samples might be asked to collaborate and share this information with other people or institutions who are conducting similar research studies.
If you were asked, how willing would you be to contribute DNA (from a blood test or saliva sample) for Research?

Very Willing (62%)
Somewhat Willing (24%)
Not Sure (7%)
Not Very Willing (2%)
Not at All Willing (3%)
Unknown (2%)

Very/Somewhat Willing = 86%
How willing would you be to share your DNA and personal information with researchers at a university or academic health center

Very Willing (59%)
Somewhat Willing (26%)
Not Sure (8%)
Not Very Willing (2%)
Not at all Willing (3%)
Unknown (2%)

Very/Somewhat Willing = 85%
How willing would you be to share your DNA and personal information with researchers working in the pharmaceutical industry?

Very Willing (35%)
Somewhat Willing (26%)
Not Sure (21%)
Not Very Willing (8%)
Not at all Willing (7%)
Unknown (2%)

Very/Somewhat Willing = 61%
How willing would you be to share your DNA and personal information with DNA repositories stored at the National Institute of Health (NIH) sponsored by the federal government?

Very Willing (44%)
Somewhat Willing (24%)
Not Sure (19%)
Not Very Willing (5%)
Not at All Willing (6%)
Unknown (2%)

Very/Somewhat Willing = 68%
If you participated in research that included your DNA, how important would it be to you to maintain control of your samples and personal information, including the right to withdraw from research?

- Very Important (59%)
- Somewhat Important (21%)
- Not Sure (10%)
- Not Very Important (4%)
- Not Important (3%)
- Unknown (3%)

Very/Somewhat Important = 80%