Responsibilities of the Patient as a Participant in Industry Sponsored, Disease Targeted Market Research

The goals of industry sponsored, disease targeted market research studies differ from the goals of clinical research. While clinical research studies are ostensibly designed to serve the community of sufferers or society in general by broadening the knowledge base, industry sponsored, disease targeted market research is often (although not always) conducted to enhance the marketing and sales of a specific product or service, or to design and/or improve communication content or vehicles. Industry sponsored, disease specific market research is not usually for the benefit of the community at large; in fact, findings are frequently proprietary and are not shared by the study sponsor with other organizations.

The market research firms and sponsors have specific obligations to participants in industry sponsored, disease targeted market research studies (refer to http://www.mria-arim.ca/STANDARDS/PDF/MRIAConduct-Dec2007REV2010.pdf for the Code of Conduct and Practices). Nevertheless, this does not absolve the patient from certain responsibilities that she/he has as a participant in these studies.

In an attempt to both protect you, as a participant, and to ensure that all parties obtain the best possible outcome from market research studies which examine issues related to specific disease, we have developed the following list which will help you in your consideration of participation in market research aimed at gathering information about you and your disease.

1. Inform yourself to the fullest extent possible *and ensure you are comfortable with the responses* regarding:
    a. the study design (for example, is this qualitative or quantitative research, how many participants are included, how have the names of potential participants been obtained, is it an international or local study, how long will your participation take, etc.)
    b. the objectives of the market research study
    c. what will be done with the results of the study (for example, will your comments be combined with responses from other participants or reported singly, will prescribing physicians be given the results or are the findings for internal purposes only)
    d. whether you will be solicited for sales or marketing purposes during the research or after

2. **You** must ensure that you are guaranteed anonymity and privacy in terms of all possible personal identifiers (name, address/location, site of medical care, etc.), in writing, unless you agree (also in writing) to have your name and/or other information released for a specific and time limited reason. You will be asked to sign a confidentiality or release form. Make sure you read and understand it before signing. Your name and contact information should not be kept on file unless you agree to this.

3. Report participation in similar studies within the last year to the sponsor before commencing the study.

4. Ensure you meet all the qualifications for the study. You may be asked to identify the drug(s) you are taking, when you were diagnosed, etc. in a 'screener' designed to ensure the sponsor has the most appropriate participants for the study. Answer accurately. If you don't meet the qualifications for this study, rest assured that another study will be coming up for which you will qualify.

5. Consider the incentive/honorarium/compensation. Does it seem to be unreasonably high? Question why the sponsor would offer such a high amount. If you are considering participation solely because you are enticed by the incentive/honorarium/compensation, reconsider your reasons for partaking in the study. Perhaps you should decline if the goals of the study do not interest you.

6. Set aside the amount of time required for the study, know where you are required to be, what you are required to bring with you and be on time.

7. Provide truthful and explicit answers to questions asked, unless you are uncomfortable with the question in which case tell the interviewer – you are not required to answer any question that makes you uneasy and you may terminate the interview at any time (although you may not receive the full compensation as a result). You are also not required to test a product or participate in additional research unless you have been advised that this is a requirement of participation and you have agreed beforehand.

8. Do not provide information which can identify another patient or healthcare worker unless you have obtained permission to do so first.

9. Income in the form of incentives or honoraria is taxable. Be aware.

10. Report any concerns regarding unethical behaviour exhibited by the market researcher or sponsor or breaches to your rights to anonymity and privacy resulting from participation in industry sponsored disease targeted market research to MRIA (Marketing Research and Intelligence Association) or Rx&D (Canada's Research Based Pharmaceutical Companies).

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