NCT NumberNCT03677739

Unique Protocol Id Pro2018001697

Consent forms for Patient and First Degree Relative (FDR)

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RUTGERS HEALTH

Rutgers, The State University of New Jersey
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CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: Facebook intervention for Young Onset Melanoma Patients and Families Patient Version

Principal Investigator: Sharon Manne, Ph.D.

STUDY SUMMARY: This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. The purpose of the research is to compare and examine the impact of 2 Facebook interventions for melanoma skin cancer patients and their first-degree relatives which includes full siblings, children who are at least 18 years old, and parents. Spouses can also participate as long as at least one of your first-degree relatives also enrolls. If you take part in the research, you will be asked to participate in a web-based, Facebook delivered intervention. Your time in the study will take approximately 9-10 months because we anticipate it will take time to form the groups and then administer 6–month post-group follow-up surveys. We may contact you by phone for a short, optional debriefing to clarify responses you gave in your evaluation, to ask questions about your experience in the Facebook group, and to gather any suggestions or changes you have for future Facebook groups. You will be compensated for completing four surveys and can earn up to $120 in Amazon e-gift cards if you complete all four surveys. We will not provide any compensation for participating in the Facebook group You will receive a $50 Amazon e-gift card for participant in the voluntary debriefing phone/zoom call. Possible harms or burdens of taking part in the study may be breach of confidentiality and any emotional distress that might accompany being asked about personal cancer risk. Possible benefits of taking part may include learning more about skin cancer, one's personal risk for skin cancer, ways to reduce one's risk for skin cancer, and the benefits of engaging in regular sunprotection behaviors, skin self-examination, and total cutaneous examination or learning more about healthy lifestyles including nutrition, physical activity, stress management and sleep. Your alternative to taking part in the research study is not to take part in it.

The information in this consent form will provide more details about the research study and what will be asked of you if you choose to take part in it. If you have any questions now, or during the study, if you choose to take part, you should feel free to ask them and should expect to be given answers you completely understand. After all of your questions have been answered and you wish to take part in the research study, you will be asked to acknowledge reading through this consent form and will indicate agreement to participate by selecting the "yes" box before continuing to the survey. You are not giving up any of your legal rights by agreeing to take part in this research or by acknowledging agreement by selecting yes at the end of this consent form.

Who is conducting this research study?
Dr. Sharon Manne, Ph.D. is the Principal Investigator of this research study. A Principal Investigator has the overall responsibility for the conduct of the research. However, there are often other individuals who are part of the research team.

Dr. Sharon Manne may be reached at Rutgers Cancer Institute of New Jersey 195 Little Albany Street New Brunswick, NJ 08903 Phone: (732) 235-6759.

Please print out this consent form if you would like a copy of it for your files.

SPONSOR OF THE STUDY: National Institutes of Health (NIH)

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Why is this study being done?
The purpose of this study is to compare and examine the impact of 2 Facebook interventions for melanoma skin cancer patients and their first-degree relatives which includes full siblings, children who are at least 18 years old, and parents. Spouses can also participate as long as at least one of your first-degree relatives also enrolls. You will be asked to participate in a web-based, Facebook delivered intervention.

Who may take part in this study and who may not?
Individuals who were diagnosed with early stage melanoma within the last 5 years, who were between the ages of 18-39 years old at the time of their diagnosis, who have completed their cancer treatment at least 3 months ago, who do not have a concurrent cancer diagnosis, who are able to read and speak English, who have access to a computer, the internet, and who have a Facebook account, and who have at least one additional family member consent and participate in the study will be eligible to participate.

Why have I been asked to take part in this study?
You are being asked to take part in this research study because you have been diagnosed with melanoma skin cancer.

How long will the study take and how many subjects will take part?
We expect your participation in the study to last approximately 9-10 months because we anticipate it will take time to form the groups and then administer the 6–month post-group follow-up surveys. We expect to recruit participants over the course of three years. Participation in this study is voluntary. The only alternative to this study is not to participate.

You will be one of approximately 583 patients in this study, along with 577 relatives. Study staff may contact you via email, Facebook, mail or phone to discuss the study.

What will I be asked to do if I take part in this study?
We will ask you to provide the contact information for your first-degree relatives that you think might be interested in our study so that we can contact them via letter, an email or telephone. If you agree to participate in this study, click next after you read this entire form to begin the online baseline survey. The survey should take around 30 minutes to complete.

After you and at least one of your first-degree relatives have completed the baseline survey, you will be randomly assigned, or assigned by 50/50 chance, to one of two Facebook groups for melanoma patients and their first-degree relatives. To join the secret Facebook group, you will either receive a friend request from our Facebook account and asked to accept it or receive an email with a link to our Facebook account and asked to "friend" us. You will then receive a notification on your Facebook account to accept the invite and join the group. We will ask for your Facebook name so we can correctly identify you when sending the friend request.

The groups are described below.

Group A: Young Melanoma Family Facebook intervention. This secret group will run for 12 weeks and will contain between 25-30 first-degree relatives and patients. The content will focus on skin cancer (skin cancer risk, self and doctor examinations, sun protection, and non-melanoma engagement posts). An interactive health educator will moderate the group.

Group B: Healthy Lifestyle Facebook intervention. This secret group will run for 12 weeks and will contain between 25-30 first-degree relatives and patients. The content will focus on healthy lifestyles (nutrition, physical activity, stress management, sleep, and general engagement posts). The group will be moderated by an

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interactive health educator.

NOTE- Both you and at least one of your first-degree relatives must consent to the study and complete a baseline survey in order to be randomly assigned to a Facebook intervention group. Both of you must consent and complete the baseline survey or else you will be excluded from the study.

Throughout the Facebook interventions, we encourage you to support and interact with other group members to the degree to which you feel comfortable. You can interact by posting in the group, sharing your personal experiences with melanoma, and commenting on and/or liking the messages we or other group members post that appeal to you. A group moderator, who is a member of the research study team, will participate in the group to engage members in discussion. After the group is over, we will ask you for feedback on the messages that were displayed in the group, the Facebook intervention itself and your experiences as a participant in the group.

After the Facebook intervention group ends, you will be sent an email link to the first follow-up survey to complete. This survey should also take around 30 minutes to complete.

Three months after the Facebook intervention group ends, you will be sent an email link to the second follow-up survey to compete. This survey should also take around 30 minutes to complete.

Six months after the Facebook intervention group ends, you will be sent an email link to the third, and final, follow-up survey to compete. This survey should also take around 30 minutes to complete.

We may contact you by phone for a short debriefing to clarify responses you gave in your evaluation, to ask questions about your experience in the Facebook group, and to gather any suggestions or changes you have for future Facebook groups. This telephone feedback debriefing is completely optional, and you can let study team members know if you are interested in taking part or not when they contact you about it. The phone call or zoom will takeapproximately 20 minutes. You will receive a $50 Amazon e-gift card for participating in the debriefing interview.

What are the risks and/or discomforts I might experience if I take part in this study?

Information you share in the Facebook group is subject to Facebook's terms of use and privacy policy, including terms of use for their website and mobile application. You should review these terms and the privacy policy carefully before choosing to download the app or use the website. Facebook may be able to collect, store, and use information about you, such as your personal information, location data, shared information, photographs, and more. We will download data from the Facebook group including posts, comments, and reactions from the group moderator, you, and other people in your group so that we can study this data to better understand how people participate and how much response our posts garnered form the group. We will not download any data from your Facebook profile or any posts to your feed – just your posts, comments, and the posts/comments you reacted to in the study Facebook group. Once the study is over, we will unfriend your Facebook account and archive the Facebook group. For more information on Facebook's Data Policy, please visit their website at https://www.facebook.com/policy.php

Are there any benefits to me if I choose to take part in this study?

The benefits of taking part in this study may be learning more about skin cancer, one's personal risk for skin cancer, ways to reduce one's risk for skin cancer, and the benefits of engaging in regular sun protection behaviors, skin self- examination, and total cutaneous examination or learning more about healthy lifestyles including nutrition, physical activity, stress management and sleep. You will be contributing to knowledge about the impacts of Family-focused Facebook interventions on melanoma patients and their first- degree relatives.

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However, it is possible that you may not receive any direct benefit from taking part in this study.

What are my alternatives if I do not want to take part in this study?
There are no alternatives available. Your alternative is to not take part in this study.

How will I know if new information is learned that may affect whether I am willing to stay in the study?
During the course of the study, you will be updated about any new information that may affect whether you are willing to continue taking part in the study. If new information is learned that may affect you after the study or your follow-up is completed, you will be contacted.

Will I receive the results of the research?
In general, we will not give you any individual results from the study. If we find something of urgent medical importance to you, we will inform you, although we expect that this will be a very rare occurrence.

Will there be any cost to me to take part in this study?
There will be no cost to you to take part in this study.

Will I be paid to take part in this study?
You will be compensated for completing the four surveys. We will send you a $30 Amazon e-gift card after both you and at least one of your first-degree relatives complete the baseline survey, a $30 Amazon e-gift card after completion of the follow-up survey immediately after the group ends, a $30 Amazon e-gift card after completion of the follow-up survey sent to you three months after the group ends, and a $30 Amazon gift card after completion of the follow-up survey sent to you six months after the group ends. We will not provide any compensation for participating in the Facebook group. You will receive a $50 Amazon e-gift card for participant in the voluntary debriefing phone/zoom call. You will be compensated a total of $120in Amazon e-gift cards if you complete all four surveys. You may also receive additional compensation if you participate in the raffles during the Facebook group.

Who might benefit financially from this research?
No one will benefit financially from this research.

How will information about me be kept private or confidential?
All efforts will be made to keep your personal information in your research record confidential, but total confidentiality cannot be guaranteed. We will use DatStat project management software to collect your survey responses. When you complete the survey online, we will know the IP address of the computer you take the survey from. We will download your responses to a secure file that requires a password to access. Only study staff will have access to the password. Study staff will request access to your email addresses, Facebook page, names, phone numbers and mailing addresses or other information that could personally identify you. We need to collect this personal information (names, phone #, mailing address and email address) so that we can send surveys and the gift cards to you as part of this study. We need your Facebook information to link you into the groups. If you're recruited througha registry, tumor variables will be accessed and recorded for data analyses purposes. You will not be personally identified in any publication. If you are not willing to provide that information to us, close outof this consent form now and do not agree to the study or begin the baseline survey questions at the end of this form. To protect your information, you will be assigned a participant code number. Your responses will be coded, and the results of the survey will be shared with the researchers and study team. Any hard copies of your data will be stored in a locked file cabinet on the 5th floor of Rutgers Cancer Institute of New Jersey in the Population Science Department. Electronic copies of data will be stored on secured servers at Rutgers Cancer Institute of New Jersey. As part of the Facebook intervention, you willbe invited to the secret group where only other members participating in the study and staff will have access. Other people will not be able to see that you are a participant in the secret group. While your

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postings in the private group are visible only to group members, by joining the group your Facebook profile and any information you have publicly available, may be visible to group members. Also, any postings that you make in the Facebook group will be visible to other members so please do not post anypersonal or health related information that you are uncomfortable with sharing. No information that can identify you will appear in any professional presentation or publication.

We will do our best to protect the confidentiality of the information we gather from you, but we cannot guarantee 100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties, including Facebook. We will utilize a Facebook add-on software called Grytics to collect your engagement (posts, comments, reactions, etc.) in the Facebook group. You will be asked to authorize to the Grytics app to access your engagement data for the duration of your study.

A description of this clinical trial will be available on ClinicalTrials.gov, as required by U.S. law. This website will not include information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

What will happen to my information or biospecimens collected for this research after the study is over?

It is not expected that you will experience any risks or discomforts from taking part in this study; however, the main potential risks are breach of confidentiality and any emotional distress that might accompany being asked about personal cancer risk. If you feel uncomfortable with a question, you can skip the question or withdraw from the study altogether. If you feel any distress associated with answering questions about skin cancer, please let the study team know. An investigator who is trained in psychology and works with cancer patients and their families can give you information about other sources of professional help. As with all research that collects protected health information, there is a risk of breach of confidentiality.

The information collected about you for this research will not be used by or distributed to investigators for other research. Identifiable data will be deleted once the study ends and any hard copies of files will be confidentially shredded.

What will happen if I do not wish to take part in the study or if I later decide not to stay in the study?
It is your choice whether to take part in the research. You may choose to take part, not to take part or you may change your mind and withdraw from the study at any time. You may also choose to skip any questions that you do not wish to answer.

If you do not want to enter the study or decide to stop taking part, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

You may also withdraw your consent for the use of data already collected about you, but you must do this in writing to:

Sharon L. Manne, Ph.D.
Associate Director of Population Science
Rutgers Cancer Institute of New Jersey
195 Little Albany Street
New Brunswick, NJ 08903
Phone: (732) 235-6759

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Who can I call if I have questions?
If you have questions, concerns, or complaints about the research, wish more information or if you feel you may have suffered a research related injury, you can contact the Principal Investigator: Sharon Manne, Department of Behavioral Sciences at (732) 235-6759

If you have questions, concerns, problems, information, or input about the research or would like to know your rights as a research subject, you can contact the Rutgers IRB Office at (973) 972-3608 or (732) 235-9806 or (732) 235-2866, or email us at IRBOffice@research.rutgers.edu, or write us at 335 George Street, Liberty Plaza Suite 3200, New Brunswick, NJ 08901.

If you have questions about your rights as a research subject and you were recruited from the Texas Cancer Registry, please contact the Texas Department of State Health Services (DSHS) Institutional Review Board (IRB) at 1-888-963-7111 (ext. 2202) or 512-776-2202.

If you were recruited from the Florida Cancer Data System and you want to talk to someone independent of the research team for questions, concerns, or complaints about the research; questions about your rights; to obtain information; or to offer input, you can contact the Florida Department of Health Institutional Review Board. An Institutional Review Board is a group of people who review research to ensure participants are protected and the research is conducted in an ethical way. You can contact the IRB at: 850-245-4585.

Who may use, share or receive my information?
The research team may use or share your information collected or created for this study with the following people and institutions:

- Rutgers University investigators involved in the study;
- University Hospital or Robert Wood University Hospital personnel to communicate information necessary for health care operations;
- Non-Rutgers investigators on the study team: (The New Jersey State Cancer Registry and its staff, The Cancer Registry of Greater California (CRGC) and its staff, MD Anderson Cancer Center and its staff, the Ohio Cancer Incidence Surveillance System and its staff, the Utah Cancer Registry and its staff, the Texas Cancer Registry and its staff, the Massachusetts Cancer Registry and its staff, the South Carolina Central Cancer Registry and its staff, the Kentucky Cancer Registry and its staff, the Tennessee Cancer Registry and its staff, the Alabama State Cancer Registry and it staff, the Iowa Cancer Registry and its staff, the North Carolina Central Cancer Registry and its staff, the Florida Cancer Data System and its staff, The Missouri Cancer Registry and Research Center (MCR-ARC) and its staff, The Greater Bay Area Cancer Registry and its staff, Montana Central Tumor Registry (MCTR) and its staff, the Cancer Data Registry of Idaho (CDRI) and its staff, and The University of Connecticut Center for mHealth and Social Media and its staff)
- DatStat program management software Qualtrics software, and members of the Rutgers Cancer Institute Population ScienceResearch Support
- Facebook
- Grytics
- The Rutgers University Institutional Review Board and Compliance Boards
- The Office for Human Research Protections in the U.S. Dept. of Health and Human Services

Those persons or organizations that receive your information may not be required by Federal privacy laws to protect it and may share your information with others without your permission, if permitted by the laws governing

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them.

Facebook and Grytics are not covered under Federal privacy laws.

Certificate of Confidentiality
This research is covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers with this Certificate may not disclose or use information, documents, or biospecimens that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or proceeding, or be used as evidence, for example, if there is a court subpoena, unless you have consented for this

use. Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research except, if there is a federal, state, or local law that requires disclosure (such as to report child abuse or communicable diseases but not for federal, state, or local civil, criminal, administrative, legislative, or other proceedings, see below); if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protectingresearch subjects.

Will I be able to review my research record while the research is ongoing?
No. We are not able to share information in the research records with you until the study is over. To ask for this

information, please contact the Principal Investigator, the person in charge of this research study.

How long will my permission last?
Your permission for the use and sharing of your health information varies based on the site in which you were recruited from.

If you were recruited from the Rutgers Cancer Institute of New Jersey, the University of Texas MD Anderson Cancer Center, the Cancer Registry of Greater California, the Ohio Cancer Incidence Surveillance System, the Texas Cancer Registry, the Massachusetts Cancer Registry, the South Carolina Central Cancer Registry, the Kentucky Cancer Registry, the Tennessee Cancer Registry, the Alabama State Cancer Registry, the Iowa Cancer Registry, the North Carolina Central Cancer Registry, the Florida Cancer Data System, The Missouri Cancer Registry and Research Center (MCR-ARC), or the Utah Cancer Registry, The Greater Bay Area Cancer Registry, Montana Central Tumor Registry (MCTR), the Cancer Data Registry of Idaho (CDRI) all identifiable data will be destroyed after study completion.

If you were recruited from the New Jersey State Cancer Registry, your permission for the use and sharing of your health information may last indefinitely as they maintain your records.

If you do not wish to take part in the research, close this website address. If you wish take part in the research, follow the directions below:

Please acknowledge that you have read through this consent form and agree to participate in this study by clicking yes below which will take you to the survey. If you do not wish to participate, click no and this form will close.

Yes
No

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Click on the link that will take you to the *[survey or questionnaire.] add LINK here.*

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CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: Facebook intervention for Young Onset Melanoma Patients and Families-FDR Version

Principal Investigator: Sharon Manne, Ph.D.

STUDY SUMMARY: This consent form is part of an informed consent process for a research study and itwill provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. The purpose of the research is to compare and examine the impact of 2 Facebook interventions for melanoma skin cancer patients and their first-degree relatives which includes full siblings, children who are at least 18 years old, parents, and spouses. If you take part in the research, you will be asked to participate in a web-based, Facebook delivered intervention. Your time in the study will take approximately 9-10 months because we anticipate it will take time to form the groups and then administer 6–month post-group follow-up surveys. We may contact you by phone for a short, optional debriefing to clarify responses you gave in your evaluation, to ask questions about your experience in the Facebook group, and to gather any suggestions or changes you have for future Facebook groups and to gather any suggestions you have. You will be compensated for completing four surveys and can earn up to $120 in Amazon e-gift cards if you complete all four. We will not provide any compensation for participating in the Facebook group. You will receive a $50 Amazon e-gift card for participant in the voluntary debriefing phone/zoom call. . Possible harms or burdens of taking part in the study may be breach of confidentiality and any emotional distress that might accompany being asked about personal cancer risk. Possible benefits of taking part may include learning more about skin cancer, one's personal risk for skin cancer, ways to reduce one's risk for skin cancer, and the benefits of engaging in regular sun protection behaviors, skinself- examination, and total cutaneous examination or learning more about healthy lifestyles including nutrition, physical activity, stress management and sleep. Your alternative to taking part in the research is to not take part in it.

The information in this consent form will provide more details about the research study and what will be asked of you if you choose to take part in it. If you have any questions now, or during the study, if you choose to take part, you should feel free to ask them and should expect to be given answers you completely understand. After all of your questions have been answered and you wish to take part in the research study, you will be asked to acknowledge reading through this consent form and will indicate agreement to participate by selecting the "yes" box before continuing to the survey. You are not giving up any of your legal rights by agreeing to take part in this research or by acknowledging agreement by selecting yes at the end of this consent form.

Who is conducting this research study?
Dr. Sharon Manne, Ph.D. is the Principal Investigator of this research study. A Principal Investigator has the overall responsibility for the conduct of the research. However, there are often other individuals who are part of the research team.

Dr. Sharon Manne may be reached at Rutgers Cancer Institute of New Jersey 195 Little Albany Street New Brunswick, NJ 08903 Phone: (732) 235-6759.

Please print out this consent form if you would like a copy of it for your files.

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Why is this study being done?

The purpose of this study is to compare and examine the impact of 2 Facebook interventions for melanoma skin cancer patients and their first-degree relatives which includes full siblings, children who are 18 years of age or older, and spouses. You will be asked to participate in a web-based, Facebook delivered intervention.

Who may take part in this study and who may not?
Individuals who have one first degree relative who was diagnosed with early stage melanoma, who are between the ages of 18-80 years, who are able to read and speak English, who have access to a computer, the internet, and who have a Facebook account, who meet sun protection eligibility requirements, and whose relative with melanoma also participates in this study are eligible.

Why have I been asked to take part in this study?
You are being asked to take part in this research study because you have a family member who has been diagnosed with melanoma skin cancer.

How long will the study take and how many subjects will take part?
We expect your participation in the study to last approximately 9-10 months because we anticipate it will take time to form the groups and then administer the 6–month post-group follow-up surveys. We expect to recruit participants over the course of three years. Participation in this study is voluntary. The only alternative to this study is not to participate.

You will be one of approximately 577 first-degree relatives, along with 583 patients. Study staff may contact you via email, Facebook, mail or phone to discuss the study.

What will I be asked to do if I take part in this study?
If you agree to participate in this study, click next after you read this entire form to begin the online baseline survey. Beginning the survey indicates that you want to participate in this study and the Facebook group intervention. The survey should take around 30 minutes to complete.

After you and your relative referring you have completed the baseline survey you will then be randomly assigned, or assigned by 50/50 chance, to one of two Facebook groups for melanoma patients and their first-degree relatives. To join the secret Facebook group, you will either receive a friend request from our Facebook account and asked to accept it or receive an email with a link to our Facebook account and asked to “friend” us. You will then receive a notification on your Facebook account to accept the invite and join the group. We will ask for your Facebook name so we can correctly identify you when sending the friend request.

The groups are described below.

Group A: Young Melanoma Family Facebook intervention. This secret group will run for 12 weeks and will contain between 25-30 first-degree relatives and patients. The content will focus on skin cancer (skin cancer risk, self and doctor examinations, sun protection, and non-melanoma engagement posts). An interactive health educator will moderate the group.

Group B: Healthy Lifestyle Facebook intervention. This secret group will run for 12 weeks and will contain between 25-30 first-degree relatives and patients. The content will focus on healthy lifestyles (nutrition, physical activity, stress management, sleep, and general engagement posts). The group will be moderated by an interactive health educator.

NOTE- Both you and your first degree relative who has been diagnosed with melanoma must consent to the study

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and complete a baseline survey in order to be randomly assigned to a Facebook intervention group. Both of you must consent and complete the baseline survey or else you will be excluded from the study.

Throughout the Facebook interventions, we encourage you to support and interact with other group members to the degree to which you feel comfortable. You can interact by posting in the group, sharing your personal experiences with melanoma, and commenting on and/or liking the messages we or other group members post that appeal to you. A group moderator, who is a member of the research study team, will participate in the group to engage members in discussion. After the group is over, we will ask you for feedback on the messages that were displayed in the group, the Facebook intervention itself and your experiences as a participant in the group.

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Six months after the Facebook intervention group ends, you will be sent an email link to the third, and final, follow-up survey to compete. This survey should also take around 30 minutes to complete.

We may contact you by phone for a short debriefing to clarify responses you gave in your evaluation, to ask questions about your experience in the Facebook group, and to gather any suggestions or changes you have for future Facebook groups. This telephone feedback debriefing is completely optional, and you can let study team members know if you are interested in taking part or not when they contact you about it. The phone call or zoom will take approximately 20 minutes. You will receive a $50 Amazon e-gift card for participating in the debriefing interview.

What are the risks and/or discomforts I might experience if I take part in this study?

Information you share in the Facebook group is subject to Facebook's terms of use and privacy policy, including terms of use for their website and mobile application. You should review these terms and the privacy policy carefully before choosing to download the app or use the website. Facebook may be able to collect, store, and use information about you, such as your personal information, location data, shared information, photographs, and more. We will download data from the Facebook group including posts, comments, and reactions from the group moderator, you, and other people in your group so that we can study this data to better understand how people participate and how much response our posts garnered form the group. We will not download any data from your Facebook profile or any posts to your feed – just your posts, comments, and the posts/comments you reacted to in the study Facebook group. Once the study is over, we will unfriend your Facebook account and archive the Facebook group. For more information on Facebook's Data Policy, please visit their website at https://www.facebook.com/policy.php

Are there any benefits to me if I choose to take part in this study?
The benefits of taking part in this study may be learning more about skin cancer, one's personal risk for skin cancer, ways to reduce one's risk for skin cancer, and the benefits of engaging in regular sun protection behaviors, skin self- examination, and total cutaneous examination or learning more about healthy lifestyles including nutrition, physical activity, stress management and sleep. You will be contributing to knowledge about the impacts of Family-focused Facebook interventions on melanoma patients and their first-degree relatives. However, it is possible that you may not receive any direct benefit from taking part in this study.

What are my alternatives if I do not want to take part in this study?
There are no alternatives available. Your alternative is to not take part in this study.

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Will I receive the results of the research?
In general, we will not give you any individual results from the study. If we find something of urgent medical importance to you, we will inform you, although we expect that this will be a very rare occurrence.

Will there be any cost to me to take part in this study?
There will be no cost to you to take part in this study.

Will I be paid to take part in this study?
You will be compensated for completing the four surveys. We will send you a $30 Amazon e-gift card after both you and your relative who referred you complete the baseline survey, a $30 Amazon e-gift card after completion of the follow-up survey immediately after the group ends, a $30 Amazon e-gift card after completion of the follow-up survey sent to you three months after the group ends, and a $30 Amazon e-card after completion of the follow-up survey sent to you six months after the group ends. We will not provide any compensation for participating in the Facebook group. You will be compensated a total of $120 in Amazon e-giftcards if you complete all four surveys. You will receive a $50 Amazon e-gift card for participant in the voluntary debriefing phone/zoom call. You may also receive additional compensation if you participate in the raffles during the Facebook group.

Who might benefit financially from this research?
No one will benefit financially from this research.

How will information about me be kept private or confidential?
All efforts will be made to keep your personal information in your research record confidential, but total confidentiality cannot be guaranteed. We will use DatStat project management software to collect your survey responses. When you complete the survey online, we will know the IP address of the computer you take the survey from. We will download your responses to a secure file that requires a password to access. Only study staff will have access to the password. Study staff will request access to your email addresses, Facebook page, names, phone numbers and mailing addresses or other information that could personally identify you. We need to collect this personal information (names, phone #, mailing address and email address) so that we can send surveys and the gift cards to you as part of this study. We need your Facebook information to link you into the groups. If you are not willing to provide that information to us, close out of this consent form now and do not agree to the study or begin the baseline survey questions at the end of this form. To protect your information, you will be assigned a participant code number. Your responses will be coded, and the results of the survey will be shared with the researchers and study team. Any hard copies of your data will be stored in a locked file cabinet on the 5th floor of Rutgers Cancer Institute of New Jersey in the Population Science Department. Electronic copies of data will be stored on secured servers at Rutgers Cancer Institute of New Jersey. As part of the Facebook intervention, you will be invited to the secret group where only other members participating in the study and staff will have access. Other people will not be able to see that you are a participant in the secret group. While your postings in the private group are visible only to group members, by joining the group your Facebook profile and any information you have publicly available, may be visible to group members. Also, any postings that you make in the Facebook group will be visible to other members so please do not post any personal or health related information that you are uncomfortable with sharing. No information that can identify you will appear in any professional presentation or publication.

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We will do our best to protect the confidentiality of the information we gather from you, but we cannot guarantee

100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties, including Facebook. We will utilize a Facebook add-on software called Grytics to collect your engagement (posts, comments, reactions, etc.) in the Facebook group. You will be asked to authorize to the Grytics app to access your engagement data for the duration of your study.

A description of this clinical trial will be available on ClinicalTrials.gov, as required by U.S. law. This website will not include information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

What will happen to my information or biospecimens collected for this research after the study is over?

It is not expected that you will experience any risks or discomforts from taking part in this study; however, the main potential risks are breach of confidentiality and any emotional distress that might accompany being asked about personal cancer risk. If you feel uncomfortable with a question, you can skip the question or withdraw from the study altogether. If you feel any distress associated with answering questions about skin cancer, please let the study team know. An investigator who is trained in psychology and works with cancer patients and their families can give you information about other sources of professional help. As with all research that collects protected health information, there is a risk of breach of confidentiality.

The information collected about you for this research will not be used by or distributed to investigators for other research. Identifiable data will be deleted once the study ends and any hard copies of files will be confidentially shredded.

What will happen if I do not wish to take part in the study or if I later decide not to stay in the study?
It is your choice whether to take part in the research. You may choose to take part, not to take part or you may change your mind and withdraw from the study at any time. You may also choose to skip any questions that you do not wish to answer.

If you do not want to enter the study or decide to stop taking part, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

You may also withdraw your consent for the use of data already collected about you, but you must do this in writing to:

Sharon L. Manne, Ph.D.
Associate Director of Population Science
Rutgers Cancer Institute of New Jersey
195 Little Albany Street
New Brunswick, NJ 08903
Phone: (732) 235-6759

Who can I call if I have questions?
If you have questions, concerns or complaints about the research, wish more information or if you feel you may have suffered a research related injury, you can contact the Principal Investigator: Sharon Manne, Department of Behavioral Sciences at (732) 235-6759

If you have questions, concerns, problems, information or input about the research or would like to know your

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rights as a research subject, you can contact the Rutgers IRB Office at: (973) 972-3608 or (732) 235-9806 or (732) 235-2866, or email us at IRBOffice@research.rutgers.edu, or write us at 335 George Street, Liberty Plaza Suite 3200, New Brunswick, NJ 08901.

If you have questions about your rights as a research subject and you were recruited from the Texas Cancer Registry, please contact the Texas Department of State Health Services (DSHS) Institutional Review Board (IRB) at 1-888-963-7111 (ext. 2202) or 512-776-2202.

If you were recruited from the Florida Cancer Data System and you want to talk to someone independent of the research team for questions, concerns, or complaints about the research; questions about your rights; to obtain information; or to offer input, you can contact the Florida Department of Health Institutional Review Board. An Institutional Review Board is a group of people who review research to ensure participants are protected and the research is conducted in an ethical way. You can contact the IRB at: 850-245-4585.

Who may use, share or receive my information?
The research team may use or share your information collected or created for this study with the following people and institutions:

- Rutgers University investigators involved in the study;
- University Hospital or Robert Wood University Hospital personnel to communicate information necessary for health care operations;
- Non-Rutgers investigators on the study team: (The New Jersey State Cancer Registry and its staff, The Cancer Registry of Greater California (CRGC) and its staff, MD Anderson Cancer Center and its staff, the Ohio Cancer Incidence Surveillance System and its staff, the Utah Cancer Registry and its staff, the Texas Cancer Registry and its staff, the Massachusetts Cancer Registry and its staff, the South Carolina Central Cancer Registry and its staff, the Kentucky Cancer Registry and its staff, the Tennessee Cancer Registry and its staff, the Alabama State Cancer Registry and its staff, the Iowa Cancer Registry and its staff, the North Carolina Central Cancer Registry and its staff, the Florida Cancer Data System and its staff, The Missouri Cancer Registry and Research Center (MCR-ARC) and its staff, / The Greater Bay Area Cancer Registry and its staff, the Montana Central Tumor Registry (MCTR) and its staff, the Cancer Data Registry of Idaho (CDRI) and its staff, and The University of Connecticut Center for mHealth and Social Media and its staff)
- DatStat program management software, Qualtrics software, and members of the Rutgers Cancer Institute Population ScienceResearch Support
- Facebook
- Grytics
- The Rutgers University Institutional Review Board and Compliance Boards
- The Office for Human Research Protections in the U.S. Dept. of Health and Human Services

Those persons or organizations that receive your information may not be required by Federal privacy laws to protect it and may share your information with others without your permission, if permitted by the laws governing them.

Facebook and Grytics are not covered under Federal privacy laws.

Certificate of Confidentiality
This research is covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers with this Certificate may not disclose or use information, documents, or biospecimens that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or

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proceeding, or be used as evidence, for example, if there is a court subpoena, unless you have consented for this use. Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else

who is not connected with the research except, if there is a federal, state, or local law that requires disclosure (such as to report child abuse or communicable diseases but not for federal, state, or local civil, criminal, administrative, legislative, or other proceedings, see below); if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protecting research subjects.

Will I be able to review my research record while the research is ongoing?
No. We are not able to share information in the research records with you until the study is over. To ask for this

information, please contact the Principal Investigator, the person in charge of this research study.

How long will my permission last?
Your permission for the use and sharing of your health information varies based on the site in which you were recruited from

If you were recruited from the Rutgers Cancer Institute of New Jersey, the University of Texas MD Anderson Cancer Center, the Cancer Registry of Greater California, the Ohio Cancer Incidence Surveillance System, theTexas Cancer Registry, the Massachusetts Cancer Registry, the South Carolina Central Cancer Registry, the Kentucky Cancer Registry, the Tennessee Cancer Registry, the Alabama State Cancer Registry, the Iowa Cancer Registry, the North Carolina Central Cancer Registry, the Florida Cancer Data System, The Missouri Cancer Registry and Research Center (MCR-ARC) and its staff, or the Utah Cancer Registry, The Greater Bay Area Cancer Registry, Montana Central Tumor Registry (MCTR), the Cancer Data Registry of Idaho (CDRI) all identifiable data will be destroyed after study completion.

If you were recruited from the New Jersey State Cancer Registry, your permission for the use and sharing of your health information may last indefinitely as they maintain your records.

If you do not wish to take part in the research, close this website address. If you wish take part in the research, follow the directions below:

Please acknowledge that you have read through this consent form and agree to participate in this study by clicking yes below which will take you to the survey. If you do not wish to participate, click no and this form will close.

Yes
No

Click on the link that will take you to the *[survey or questionnaire.] add LINK here.*