Medical University of South Carolina
CONSENT TO BE A RESEARCH SUBJECT

TITLE OF RESEARCH:
Managing **A**s**T**hma **An**d **O**besity **R**elated **S**ymptoms **(MATADORS)** study: An mHealth intervention to facilitate symptom management among youth

Concise Summary

You and your child are being asked to volunteer for a research study. Research studies are voluntary, and you do not have to participate. The purpose of this research study is to help us better understand the challenges faced by youth with asthma and obesity and their primary caregivers. An app downloaded to your child's phone will track information related to movement, sleep and overall how they feel each day. We will use information from this study to refine a mobile health application to help youth and their caregivers self-manage their condition. The mobile health application will use smartphones and will help connect patients and their families with information, education, and healthcare resources, including access to providers to better manage their health. Your child will be randomized into one of two groups. You will have a 50:50 chance of being in either group (like the flip of a coin).

If you agree to volunteer for this study, you and your child will be asked to complete some questionnaires. Your child will also be asked to install the MATADORS app on a smartphone (theirs or yours) and log into it daily for four weeks to share how they are feeling each day, what they are doing, what medicines they took, and to access the educational information. Your child will also wear a Fitbit for 30 days to monitor their physical activity and sleep patterns.

There will be no direct benefit to you or your child by participating in this research. Potential risks from participating in this research study include loss of confidentiality and privacy. It could be possible that some of the questions asked could be emotionally upsetting and or you and your child could become physically bored from participating. You and your child can refuse to answer any questions. If you are interested in learning more about this study, please continue to read below.

A. PURPOSE OF THE RESEARCH

Please read this consent form carefully and take your time making your decision. As your study doctor or study staff discusses this consent form with you, please ask him/her to explain any words or information that you do not clearly understand. You and your child are being asked to participate in this study because your child has asthma and is considered overweight or obese for their age/gender. Youth with asthma and who are overweight are at increased risk of health problems as they become adults. This study hopes to learn more about how to help youth with asthma and who are overweight and their primary caregivers, to self-manage their condition through a mobile health application. The app will track daily medication and symptoms. The MATADORS app is being developed by the study team and feedback from this study will help refine the app. Our long-term goal is to provide youth and their caregivers with the resources needed to self-manage their conditions and reduce the risks of further disease as they enter adulthood. This study is sponsored by National Institutes of Health and

the National Institute of Nursing Research. The investigator in charge of this study at MUSC is Dr. Michelle Nichols. Approximately 60 people (30 youth-caregiver pairs) will take part in this study.

B. PROCEDURES

If you and your child agree to be in this study, the following will happen:

1. We will use medical chart review to access your child's height and weight measurements. We will ask you to provide current height and weight measurements for current verification. This will help us know how your child's body size compares to other children based on their age and gender). We will also ask if your child has a current diagnosis of asthma that requires prescribed inhaler medication. Your child will need to have a body mass index of 85% or more (based on their age and gender), have a diagnosis of asthma, and be taking one or more prescribed inhaler medications to be eligible to participate.
2. **Visit 1:** You and your child will each be asked to complete several questionnaires. The first questionnaire will ask information about you or your child, such as age, gender, race, ethnicity, education, medication history, health conditions your child has, insurance information, and details about where your family lives. The next questionnaire will ask your child 18 questions about their understanding of health terms and takes about 2 minutes to complete. We will also ask you and your child to complete questionnaires about your child's symptoms. These include questions about pain, fatigue, depression, anxiety, and self-management of their disease. These questionnaires can be completed in person, over the phone, via telehealth, or online.
3. After the initial questionnaires are completed, your child will be randomly assigned to one of two groups. This means that your child has a 50/50 chance (like flipping a coin) of being in either group. Neither the researchers nor you (or your child) will make the choice to which group you are assigned. The two groups are Group A and Group B. Group A will only have access to the basic features within the app and not the educational information. Group B will have access to the entire app, including the educational information.
4. Both Groups: Your child will then be instructed on installing and using the MATADORS app. We will ask your child to log into the app daily for one month (about 4 weeks). This app will ask your child to answer questions each day on how they are feeling and what medications your child took. This will take approximately 5-10 minute each day. Your child will also be asked to install the Fitbit app and wear the activity tracker that we provide for the 4-week duration of the study so we can monitor your child's physical activity and sleep patterns. We will also ask you to return the Fitbit at the end of the 4-weeks. Your child will be asked to make a short video, one-time only during the 4-week period, while taking their inhaler, so we can look at your child's inhaler technique and provide your child with feedback.
5. **Group B** will be asked to meet once weekly (briefly by phone or telehealth) for nurse-led guided support during the study period. This will be a chance to check in to see how your child is doing and answer any questions or problems you may have with the app, Fitbit, or study. Youth in Group B will also be asked to enter their daily activities, either through a short daily diary entry that can be through a video, photo, or voice entry. Your child will be prompted to use the educational information in the app to learn more about asthma, managing their disease, and in maintaining a healthy lifestyle.

6. **Visit 2 (Week 4):** At the end of the 30-day (week 4) study period, you and your child will be asked to complete the same questionnaires from visit one on your child's symptoms. These include questions about pain, fatigue, depression, anxiety, and self-management of their disease. These questionnaires can be completed in person, over the phone, via telehealth, or online.

7. **Visit 3 (Week 8):** You and your child will be asked to complete the same questionnaires from visits 1 & 2 on your child's symptoms. These include questions about pain, fatigue, depression, anxiety, and self-management of their disease. These questionnaires can be completed in person, over the phone, via telehealth, or online. You and your child will be asked to participate in an interview together with the study investigator. The interview will be audio-recorded and last about 45 minutes. During the interview, we will ask you and your child about life with asthma, thoughts and recommendations about the app and use of the Fitbit, and how we can make it better for youth and parents to self-manage their child's disease. The interviews can be conducted in person or through a video conference. Only the audio portion of the interview will be recorded regardless of where it is completed.

C. DURATION

Participation in the study will take about 3 visits over a period of 2 months.

D. RISKS AND DISCOMFORTS

There is a risk of a loss of confidentiality of you and your child's personal information as a result of participation in this study.

Loss of privacy: There is a risk of loss of privacy from participation in this study. Your privacy and the privacy of your child are very important to us, and we will make every effort to protect it. Information we collect from you and your child, including information we collect through the app and Fitbits, will be stored electronically on secure, encrypted servers at MUSC, and we will limit access to this information to authorized personnel.

All research records gathered from your child's medical record, from questionnaires, the app, and from the interview will have any information that could directly identify you or your child removed. Research information that identifies you may be shared with the MUSC Institutional Review Board (IRB) and others who are responsible for ensuring that researchers comply with laws and regulations related to conducting research.

Emotional distress: Some of the questions may be upsetting or make you or your child feel uncomfortable. You or your child can always refuse to answer a question.

Physical fatigue: Completing the questionnaires and interviews may be tiring for some participants You will be given ample time to compete the questionnaires or interview and you may take breaks throughout the process.

Randomization: Your child will be randomly assigned to one of two groups. This means that your child has a 50/50 chance (like flipping a coin) of being in either group. Neither the researchers nor you (or your child) will make the choice to which group you are assigned. The two Groups are Group

A and Group B and the treatment of one group may may prove to be more or less effective than the other.

E. MEDICAL RECORDS AND/OR CERTIFICATE OF CONFIDENTIALITY

Information about your or your child's study participation will not be in your medical record. This means that neither your research participation nor any of your research results will be included in any MUSC medical record.

F. CERTIFICATE OF CONFIDENTIALITY

This research is covered by a Certificate of Confidentiality from the Federal government. This means that the researchers may not disclose information or biospecimens that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, nor can the information or biospecimens be used as evidence, unless you have consented to this disclosure. Information or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research unless you have consented to the disclosure. More specifically, identifiable information or biospecimens will not be shared with your medical providers who are not involved in this research unless you authorize the study to disclose information to them, or if it is used for other scientific research, as allowed by federal regulations protecting research subjects.

Information about your study participation will not be in your MUSC medical record. This means that neither your research participation nor any of your research results will be included in any MUSC medical record. A Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you want your research information released to an insurer, medical care provider, or any other person not connected with the research, you must authorize the researchers to release it.

The Certificate of Confidentiality will not be used to prevent disclosure as required by federal, state, or local law. Examples of required disclosure include: child abuse and neglect, or harm to self and others, but there could be others.

Finally, a Certificate may not be used to withhold information from the Federal government needed for auditing or evaluating Federally funded projects or information needed by the FDA.

G. BENEFITS

There will be no direct benefit to you from participating in this study. However, it is hoped that the information gained from the study will help in the treatment of future patients with conditions like your child will help the researcher learn more about how to best help youth with asthma and obesity and their caregivers self-manage their conditions using a mobile health application.

H. COSTS

Normal cellular and data usage rates will apply to your mobile device charges. You may incur costs related to study participation as a result of downloading and using the Fitbit and MATADORS apps.

I. PAYMENT TO PARTICIPANTS

In return for your time and effort, you and your child will be paid for participation in this study. If you do not complete the study, you and your child will receive payment for each completed visit as listed below. Payment will be made in the form of a check and may take several weeks to arrive. We will ask for your social security number in order to complete check payments.

Both groups (including caregivers): You and your child will be each be paid $30 for Visit 1 and then $25 for each Study visit (weeks 4 and 8). Each member (parent and child) who completes the post-study interview will also be paid an additional $25. The potential total for caregivers/parents who complete all study activities is $105. Details on the Caregiver payment are listed in the table below

Caregiver Payment (Group A & B)	**Amount for Completion of Study Activity**
Visit 1	$30
Visit 2 (week 4)	$25
Visit 3 (week 8)	$25
Post-study interview	$25
Total	$105 (maximum amount for completion of all study activities). The total amount paid will depend on the actual study visits completed.

Group A Youth: In addition to the amounts listed above, youth randomized to Group A will receive an additional $1/day for logging into the MATADORS app, answering the daily questions and reporting medication use, and wearing the Fitbit for a maximum of 30 days. The amount paid will be pro-rated based on the total number of days these study activities are completed. Youth will also receive an additional $10 for completing and uploading a one-time video of them taking their inhaler medication to view their technique. Group A youth may receive up to $145 for completion of all study activities. Details on the Group A Youth payment are listed in the table below.

Group A Youth Payment	**Amount for Completion of Study Activity**
Visit 1	$30
Visit 2 (week 4)	$25
Visit 3 (week 8)	$25
Daily symptom reporting (answering questions), medication reporting, and Fitbit use	$1/day for up to 30 days ($30 max)
One time video inhaler technique upload	$10
Post-study interview	$25
Total	$145 (maximum amount for completion of all study activities). The total amount paid will depend on the actual study visits completed.

Group B Youth: In addition to the amounts listed above, youth randomized to Group B will receive up to an additional $4/day for logging into the MATADORS app, answering the daily questions and reporting medication use, uploading the daily diary entry, and wearing the Fitbit for a maximum of 30 days. The amount paid will be pro-rated based on the total number of days these study activities are completed. Youth will also receive an additional $10 for completing and uploading a one-time video of

them taking their inhaler medication to view their technique. Group B youth may receive up to $235 for completion of all study activities. Details on the Group B Youth payment are listed in the table below.

Group B Youth Payment	Amount for Completion of Study Activity
Visit 1	$30
Visit 2 (week 4)	$25
Visit 3 (week 8)	$25
Daily symptom reporting (answering questions)	$1/day for up to 30 days ($30 max)
Daily medication reporting	$1/day for up to 30 days ($30 max)
Daily video/photo/voice diary entry	$1/day for up to 30 days ($30 max)
Daily Fitbit use	$1/day for up to 30 days ($30 max)
One time video inhaler technique upload	$10
Post-study interview	$25
Total	$235 (maximum amount for completion of all study activities). The total amount paid will depend on the actual study visits completed.

Payments that you receive from MUSC for participating in a research study are considered taxable income per IRS regulations. Payment types may include, but are not limited to: checks, cash, gift certificates/cards, personal property, and other items of value. If the total amount of payment you receive from MUSC reaches or exceeds $600.00 in a calendar year, you will be issued a Form 1099.

J. ALTERNATIVES

Your alternative is to not participate in this study.

K. DATA SHARING

Information about you and your child (including your identifiable private information) may have all of your identifiers removed and used for future research studies or distributed to other researchers for future research without additional informed consent from you or your legally authorized representative.

L. DISCLOSURE OF RESULTS

Clinically relevant information collected about your child's inhaler technique will be shared with you and your child by the study team. This will be done to provide you and your child with feedback on their current inhaler technique and we will offer recommendations, as needed. No other research results will be shared with you or your child.

M. AUTHORIZATION TO USE AND DISCLOSE (RELEASE) MEDICAL INFORMATION

As part of this research study, your study doctor and his/her research team will keep records of your participation in this study.

The health information MUSC may use or disclose (release) for this research study includes information in your medical record, results of physical exams, medical history, lab tests or certain health information indicating or relating to your condition.

Your study doctor and his/her research team will use and disclose (release) your health information to conduct this study. The health information listed above may be used by and/or disclosed (released) to the following, as applicable:

- The sponsor of the study including its agents such as data repositories or contract research organizations monitoring the study;
- Other institutions and investigators participating in the study;
- Data Safety Monitoring Boards;
- Accrediting agencies;
- Clinical staff not involved in the study whom may become involved if it is relevant;
- Parents of minor children if less than 16 years old. Parents of children 16 years old or older require authorization from the child; or
- Health insurer or payer in order to secure payment for covered treatment;
- Federal and state agencies and MUSC committees having authority over the study such as:

    - The Institutional Review Board (IRB) overseeing this study; Committees with quality improvement responsibilities; Office of Human Research Protections; Food and Drug Administration; National Institutes of Health or Other governmental offices, such as a public health agency or as required by law.

Those persons who receive your health information may not be required by Federal privacy laws (such as the Privacy Rule) to protect it and may share your information with others without your permission, if permitted by laws governing them. You do not have to sign this consent form. If you choose not to sign, it will not affect your treatment, payment or enrollment in any health plan or affect your eligibility for benefits. However, you will not be allowed to be a participant in this research study.

You will be given a copy of this consent form. Your authorization will expire at the conclusion of this study or, if you are participating in a study designed for the development of a drug or device, your authorization will remain in effect until the drug or device is approved by the FDA or until the company's application to study the drug/device is withdrawn. You have the right to withdraw your agreement at any time. You can do this by giving written notice to your study doctor. If you withdraw your agreement, you will not be allowed to continue participation in this research study. However, the information that has already been collected will still be used and released as described above. You have the right to review your health information that is created during your participation in this study. After the study is completed, you may request this information.

Your health information will be used or disclosed when required by law. Your health information may be shared with a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury or disability and for conducting public

health surveillance, investigations or interventions. No publication or public presentation about the research study will reveal your identity without another signed authorization from you.

If you have questions or concerns about this Authorization or your privacy rights, please contact MUSC's Privacy Officer at (843) 792-8740.

Regulations require that you be given a copy of the MUSC Notice of Privacy Practices (NPP) describing the practices of MUSC regarding your health information. One can be found at the end of this form.

N. EMPLOYEE PARTICIPATION

Your participation or discontinuance will not constitute an element of your job performance or evaluation, nor will it be a part of your personnel record at this Institution.

O. CLINICAL TRIALS.GOV

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

P. FUTURE CONTACT

The researcher in charge of this study might like to contact you in the future about other research opportunities. Please initial by your choice below for paper consents, or scroll down to the bottom of the screen and select your choice electronically:

____Yes, I agree to be contacted

____No, I do not agree to be contacted

Results of this research will be used for the purposes described in this study. This information may be published, but you will not be identified. Information that is obtained concerning this research that can be identified with you will remain confidential to the extent possible within State and Federal law. The investigators associated with this study, the sponsor, and the MUSC Institutional Review Board for Human Research will have access to identifying information. All records in South Carolina are subject to subpoena by a court of law.

In the event that your child is injured as a result of participation in this study, you should immediately take your child to the emergency room of the Medical University Hospital, or in case of an emergency go to the nearest hospital and tell the physician on call that your child is in a research study. They will call your child's study doctor who will make arrangements for your child's treatment. If the study sponsor does not pay for your child's treatment, the Medical University Hospital and the physicians who render treatment to your child will bill your insurance company. If your insurance company denies coverage or insurance is not available, you will be responsible for payment for all services rendered to your child.

Your participation in this study is voluntary. You may refuse to take part in or stop taking part in this study at any time. You should call the investigator in charge of this study if you decide to do this. Your decision not to take part in the study will not affect your current or future medical care or any benefits to which you are entitled.

The investigators and/or the sponsor may stop your participation in this study at any time if they decide it is in your best interest. They may also do this if you do not follow the investigator's instructions.

Volunteers Statement

I have been given a chance to ask questions about this research study. These questions have been answered to my satisfaction. If I have any more questions about my child's participation in this study or study related injury, I may contact **Dr. Michelle Nichols at (843) 792-1802** . I may contact the Medical University of SC Patient and Family Care Liaison (843) 792-5555 concerning medical treatment.

If I have any questions, problems, or concerns, desire further information or wish to offer input about my child's rights as a research subject in this study, I may contact the Medical University of SC Institutional Review Board for Human Research IRB Manager or the Office of Research Integrity Director at (843) 792-4148. This includes any questions about my rights as a research subject in this study.

I agree to participate in this study. I have been given a copy of this form for my own records.

If you wish to participate, please sign below for paper consents or scroll to the bottom of the screen to provide an electronic signature.

_____ _____
Signature of Person Obtaining Consent Date *Printed Name of Minor Participant

_____

Signature of Adult Participant Date

_____
Signature of Participant's Personal Representative (if applicable) Date

_____
Printed Name of Personal Representative (if applicable)

Relationship: ___ Spouse ___ Parent ___Next of Kin ___Legal Guardian* ____ DPOA for Healthcare*

**(If you are the health care agent or guardian, please provide proof of your authority to act on behalf of the patient)*

*For Minors 12-17 years of age: "My participation has been explained to me, and all of my questions have been answered. I am willing to participate."
Signature: _____

MUSC
Medical University of South Carolina

NOTICE OF PRIVACY PRACTICES

MUSC Organized Health Care Arrangement (OHCA)

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESSS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

UNDERSTANDING YOUR PROTECTED HEALTH INFORMATION (PHI)
The Medical University of South Carolina and its affiliates (including but not limited to the Medical University Hospital Authority, MUSC Physicians, MUSC Physicians Primary Care, MUSC Health Partners, MUSC Health Alliance, MUSC Strategic Ventures, LLC, and MUSC Strategic Ventures (MSV) Health, Inc.) participate in a clinically integrated health care setting. As a result of this clinical integration, these organizations function as an Organized Health Care Arrangement (OHCA) as defined by the Health Insurance Portability and Accountability Act (HIPAA). For purposes of this notice, the members of the MUSC OHCA are collectively referred to in this document as "MUSC." **We collect, receive, or share this information about your past, present or future health condition to provide health care to you, to receive payment for this health care, or to operate the hospital and/or clinics.**

OUR PLEDGE REGARDING YOUR HEALTH INFORMATION
MUSC is committed to protecting the privacy of health information we create and obtain about you. This Notice tells you about the ways in which we may use and disclose health information about you. It also describes your rights and certain obligations we have regarding the use and disclosure of your health information. We are required by law to: (i) make sure your health information is protected; (ii) give you this Notice describing our legal duties and privacy practices with respect to your health information; and (iii) follow the terms of the Notice that is currently in effect.

HOW WE MAY USE AND RELEASE YOUR PROTECTED HEALTH INFORMATION (PHI) –

A. The following uses do NOT require your authorization, except where required by SC law:
1. For treatment. Your PHI may be discussed by caregivers to determine your plan of care. For example, the physicians, nurses, medical students and other health care personnel may share PHI in order to coordinate the services you may need.
2. To obtain payment. We may use and disclose PHI to obtain payment for our services from you, an insurance company or a third party. For example, we may use the information to send a claim to your insurance company.
3. For health care operations. We may use and disclose PHI for hospital and/or clinic operations. For example, we may use the information to review our treatment and services and to evaluate the performance of our staff in caring for you.
4. Business Associates. Your medical information could be disclosed to people or companies outside our Health System who provide services. These companies typically are required to sign special confidentiality agreements before accessing your information. They are also subject to fines by the federal government if they use/disclosure your information in a way that is not allowed by law.
5. For public health activities. We report to public health authorities, as required by law, information regarding births, deaths, various diseases, reactions to medications and medical products.
6. Victims of abuse, neglect, domestic violence. Your PHI may be released, as required by law, to the South Carolina Department of Social Services when cases of abuse and neglect are suspected.
7. Health oversight activities. We will release information for federal or state audits, civil, administrative or criminal investigations, inspections, licensure or disciplinary actions, as required by law.
8. Judicial and administrative proceedings. Your PHI may be released in response to a subpoena or court order.
9. Law enforcement or national security purposes. Your PHI may be released as part of an investigation by law enforcement or for continuum of care when in the custody of law enforcement.
10. Military and Veterans. If you are a member of the U.S. or foreign armed forces, we may release your medical information as required by military command authorities.
11. Uses and disclosures about patients who have died. We may provide medical information to coroners, medical examiners and funeral directors so they may carry out their duties.
12. For purposes of organ donation. As required by law, we will notify organ procurement organizations to assist them in organ, eye or tissue donation and transplants.
13. Research. We may use and disclosure your medical information for research purposes. Most research projects are subject to Institutional Review Board (IRB) approval. The law allows some research to be done using your medical information without requiring your written approval.
14. To avoid harm. In order to avoid a serious threat to the health or safety of a person or the public, we may release limited information to law enforcement personnel or persons able to prevent or lessen such harm.
15. For workers compensation purposes. We may release your PHI to comply with workers compensation laws.
16. Marketing. We may send you information on the latest treatment, support groups, reunions, and other resources affecting your health.
17. Fundraising activities. We may use your PHI to communicate with you to raise funds to support health care services and educational programs we provide to the community. You have the right to opt out of receiving fundraising communications with each solicitation.
18. Appointment reminders and health-related benefits and services. We may contact you with a reminder that you have an appointment.
19. Disaster Relief Efforts. We may disclose your medical information to an entity assisting in disaster relief efforts so that your family can be notified about your condition.
Note: incidental uses and disclosures of PHI sometimes occur and are not considered to be a violation of your rights. Incidental uses or disclosures are by-products of otherwise permitted uses or disclosures which are limited in nature and cannot be reasonably prevented.

B. You may object to the following uses of PHI:
1. Inpatient hospital directories. Unless you tell us not to, we may include your name, location, general condition and religious affiliation in our patient directory so your family, friends and clergy can visit you and know how you are doing.

2. Information shared with family, friends or others. Unless you tell us not to, we may release your PHI to a family member, friend, or other person involved with your care or the payment for your care.
3. Health plan. You have the right to request that we not disclose certain PHI to your health plan for health services or items when you pay for those services or items in full.

C. Your prior written authorization is required (to release your PHI) in the following situations:
You may revoke your authorization by submitting a written notice to the privacy contact identified below. If we have a written authorization to release your PHI, it may occur before we receive your revocation.
1. Any uses or disclosures beyond treatment, payment or healthcare operations and not specified in parts A & B above.
2. Mental Health Records unless permitted under an exception in section A.
3. Substance Use Disorder Treatment records unless permitted under an exception in section A.
4. Any circumstance where we seek to sell your information.

WHAT RIGHTS YOU HAVE REGARDING YOUR PHI

Although your health record is the physical property of MUSC, the information belongs to you, and you have the following rights with respect to your PHI:
A. The Right to Request Limits on How We Use and Release Your PHI. You have the right to ask that we limit how we use and release your PHI. We will consider your request, but we are not always legally required to accept it. If we accept your request, we will put any limits in writing and abide by them except in emergency situations. Your request must be in writing and state (1) the information you want to limit; (2) whether you want to limit our use, disclosure or both; (3) to whom you want the limits to apply, for example, disclosures to your spouse; and (4) an expiration date**.**
B. The Right to Choose How We Communicate PHI with You. You have the right to request that we communicate with you about PHI and/or appointment reminders in a certain way or at a certain location (for example, sending information to your work address rather than your home address). You must make your request in writing and specify how and where you wish to be contacted. We will accommodate reasonable requests.
C. The Right to See and Get Copies of Your PHI. You have the right to inspect and/or receive a copy (an electronic or paper copy) of your medical and billing records or any other of our records used to make decisions about your care. You must submit your request in writing. If you request a copy of this information, we may charge a cost-based fee. MUSC will act on a request for access or provide a copy usually within 30 days of receipt of the request. We may deny your request in limited circumstances. If you are denied access to your records, you may request that the denial be reviewed by a licensed health care professional. Additionally, we may use and disclose information through our secure patient portal which may allow you to view and communicate with certain health care providers in a secure manner. For more information see our https://mychart.musc.edu/mychart/
D. The Right to Get a List of Instances of When and to Whom We Have Disclosed Your PHI. This list may not include uses such as those made for treatment, payment, or health care operations, directly to you, to your family, or in our facility directory as described above in this Notice of Privacy Practices. This list also may not include uses for which a signed authorization has been received or disclosures made more than six years prior to the date of your request.
E. The Right to Amend Your PHI. If you believe there is a mistake in your PHI or that a piece of important information is missing, you have the right to request that we amend the existing information or add the missing information. You must provide the request and your reason for the request in writing. We may deny your request in writing if the PHI is correct and complete or if it originated in another facility's record. Notification will be provided within 60 days.
F. The Right to Receive a Paper or Electronic Copy of This Notice: You may ask us to give you a copy of this Notice at any time. For the above requests (and to receive forms) please contact: Health Information Services (Medical Records), Attention: Release of Information / 169 Ashley Avenue / MSC 349 / Charleston, SC 29425. The phone number is (843) 792-3881.
G. The Right to Revoke an Authorization. If you choose to sign an authorization to release your PHI, you can later revoke that authorization in writing. This revocation will stop any future release of your health information except as allowed or required by law.
H. The Right to be Notified of a Breach. If there is a breach of your unsecured PHI, we will notify you of the breach in writing.

HEALTH INFORMATION EXCHANGES

MUSC, along with other health care providers, belongs to health information exchanges. These information exchanges are used in the diagnosis and treatment of patients. As a member of these exchanges, MUSC shares certain patient health information with other health care providers. Should you require treatment at another location that is a part of one of these exchanges, that provider may gather historical health information to assist with your treatment. You have the option of saying that this cannot be done. If you choose not to take part in these alliances, please contact the MUSC Privacy Office at 792-4037.

HOW TO COMPLAIN ABOUT OUR PRIVACY PRACTICES

If you think your privacy rights may have been violated, or you disagree with a decision we made about access to your PHI, you may file a complaint with the office listed in the next section of this Notice. **Please be assured that you will not be penalized and there will be no retaliation for voicing a concern or filing a complaint. We are committed to the delivery of quality health care in a confidential and private environment.**

PERSON TO CONTACT FOR INFORMATION ABOUT THIS NOTICE OR TO COMPLAIN ABOUT OUR PRIVACY PRACTICES

If you have any questions about this Notice or any complaints about our privacy practices please call the Privacy Officer (843) 792-4037, the Privacy Hotline (800) 296-0269, or contact in writing: HIPAA Privacy Officer / 169 Ashley Avenue / MSC 332 / Charleston SC 29425. You also may send a written complaint to the U.S. Dept. of Health and Human Services, Office for Civil Rights. The address will be provided at your request or by visiting www.hhs.gov/ocr/privacy/hipaa/complaints/.

CHANGES TO THIS NOTICE

We reserve the right to change the terms of this Notice at any time. The changes will apply to all existing PHI we have about you.. This Notice will always contain the effective date and may be reviewed at http://academicdepartments.musc.edu/musc/about/compliance/privacy.html

EFFECTIVE DATE OF THIS NOTICE

This Notice went into effect on April 14, 2003 and was last revised on August 2018.