

**USE AND DISCLOSE OF PROTECTED HEALTH INFORMATION (PHI) AND  
 PATIENT AND FAMILY SUPPORT GROUPS**

Support groups are extremely helpful for patients and their families to learn about their diseases and treatment and provide emotional support. Making these groups available to our patients and their families is a component of providing patient care. Therefore, informing patients of this opportunity is important.

However, using patient information to generate a list to provide support group information is subject to privacy laws, including HIPAA. As administrators and clinicians contemplate whether to establish a patient support group or are presently holding them, it is important that we use and disclose protected health information (PHI) for these purposes in a HIPAA compliant manner. The following provides guidance for you to understand how and when you can use patient information.

#	Question	Answer
1.	Can I search through our information systems (i.e. OACIS, EPIC) for patients who I want to receive materials and information for a UCMC sponsored support group?	No, but you can request a list of patients in the clinic with the disease or treatment that the support group is intended to serve. The list would be limited to patients being cared for in the clinic or department sponsoring the support (see question 2 to learn how to obtain the list).
2.	What should I do if I want to obtain a list of patients (e.g. including names, address, and phone number) that are in my clinic who have a diagnosis for which I would like to start a UCMC sponsored support group?	To request PHI for the purpose of providing patients with information about a support group operating from a patient's clinic, use the UCMC Trusted Requestor Form, which can be accessed at <a href="http://hipaa.bsd.uchicago.edu/TR_Form.pdf">http://hipaa.bsd.uchicago.edu/TR_Form.pdf</a> . The Form should be faxed to the HIPAA Program Office (HPO) at 2-6278 for review.
3.	Once I identify the patients, may I contact them by telephone to ask if they would be interested in joining a UCMC sponsored support group?	Yes, you may contact patients in your clinic that are <u>currently</u> being treated for the relevant condition/disease by telephone; however you should speak with the patient directly. <b>Do not leave a message on the patient's answering machine.</b> Please refer to the HPO Telephone Message Guidelines for additional information <a href="http://hipaa.bsd.uchicago.edu/phone_guidelines.html">http://hipaa.bsd.uchicago.edu/phone_guidelines.html</a>

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4.	Can I send a letter to my patients asking them if they are interested in joining a UCMC sponsored support group?	Yes, a letter can be mailed to the patients; however the HPO should review the letter and provide guidance before it is mailed. Please forward a draft of the letter to the HPO by email at <a href="mailto:hpo@bsd.uchicago.edu">hpo@bsd.uchicago.edu</a> . The exterior mailing should not contain any information about the group, disease, or treatment (e.g. do not use: postcards, return addresses that contain the name of the support group, self mailer brochures about the support group, etc.).
5.	Can I post a support group sign-up sheet in the clinic waiting room asking the patient to provide his/her full name, address, phone number, and email address?	No. This creates a public posting of PHI. Alternatively, you can post general flyers in the clinic sponsoring the support group that lists a person to contact for more information or directs the patient to speak to someone in the clinic who can capture the patient's information in a more private manner.
6.	Does this guidance apply when I am planning, assisting, and/or leading an outside support group (e.g. Defeat Diabetes Foundation's support group)?	Generally no. Contact the HPO for assistance.
7.	Can UCMC share patient information with other participants in the UCMC sponsored support group and visitors?	No. UCMC representatives <u>may not</u> disclose any patient information to participants or group visitors, including information about each other.  However, support group participants may choose to sign up on a "support group email sheet" which will allow the group leader to send via email announcements and/or information related to future support group meetings. <i>A template is included on page 5.</i>  Support group participants can self disclose and share information with others as they wish.

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#	Question	Answer
8.	Can we invite a representative from a 3 <sup>rd</sup> party organization such as a not-for-profit organization that offers additional services (i.e. (Y-ME, Muscular Dystrophy Association) to participate in the UCMC sponsored support group?	<p>Yes, but only if the individual and his/her organization is disclosed to all participants in advance of the meeting as well as before the meeting begins. It would be prudent to have the outside representative wear a badge indicating the name of the organization during the meeting.</p> <p>In addition, consistent with Q/A 7, UCMC personnel <u>must not</u> share patient information before, during, or after the meeting to the 3<sup>rd</sup> party without first obtaining a patient written authorization. However, the patients may provide their own PHI to the 3<sup>rd</sup> party voluntarily.</p>
9.	Is there anything I need to do if a reporter contacts me to do a news story on a UCMC sponsored support group, to interview some of the patients, or to take pictures of the support group?	<p>Yes. Upon receiving the request, immediately contact the UCMC Public Affairs Department at 2-6241 to coordinate between UCMC and the reporter. In addition:</p> <ol style="list-style-type: none"> <li>1. Contact the HPO so it can meet with the reporter to discuss the importance of patient privacy and confidentiality.</li> <li>2. Prior to beginning the support group, announce who the person is and what organization he/she is representing.</li> <li>3. All patients wishing to participate in the support group or wanting to be photographed and/or interviewed <u>must</u> sign an <b>Authorization To Use and Disclose Health Information For Marketing or Media</b>. The authorization can be obtained from Public Affairs and should be kept in the patient's medical record. The HPO doesn't need a copy of the authorization form.</li> <li>4. Participants who do not sign an authorization should be excluded from the session or wearing a clear indicator of nonparticipation (i.e. color coded badge).</li> </ol>

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#	Question	Answer
10.	While in a support group session, can I directly ask a patient to self-disclose their health information in front of the group?	No. It is not advised to single out a patient in front of the group. Individuals may initially be very sensitive and uncomfortable with sharing their health information and personal stories. It is recommended that before starting the group, you should invite all participants to share their stories – to the extent they feel comfortable.
11.	Is it permissible to ask support group participants if they want to wear name tags?	Yes, you can ask participants if they want to wear name tags. However, it is recommended that participants who wish to wear name tags only use their first name. Name tags should not refer to the support group name or related disease or treatment. It is not required that participants wear name tags.
12.	Should participants be required to sign a confidentiality agreement or authorization form stating that they will not discuss or disclose any patient specific information outside the group?	No. As long as the information provided in this guidance is followed.
13.	Is it permissible for the UCMC physician or representative to provide patient specific medical advice during a support group session?	No. Patient specific medical advice should only be given when the patient is being treated by the clinician during a regularly scheduled appointment.

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**(Fill in Name of Group) Support Group**

**Email Sign Up Sheet**

This is a sign up sheet for an email distribution list for this support group. By including your information on this list, you may receive email communications announcing future meetings and/or information of interest from the support group leader. Your email address may be available to everyone on this distribution list.

**Do not sign up if you do not want others to know you are on this support group email distribution list.**

Printed Name	Email Address