

HANDS OF HUMANITY STUDY – STUDY DOCUMENTS

ITEM 1 - 'HANDS OF HUMANITY' STUDY – PARTICIPANT INFORMATION LEAFLET

We would like to invite you to take part in a research study led by Dr. Imelda Galvin and Dr. Christopher Meyer, both physicians in the Critical Care Department of Kingston Health Sciences Centre and Queens University. Taking part in this study is entirely voluntarily and you may withdraw from the study at any time. Your decision to take part or not will not in any way influence the care you and your family members receive. The study is described below

What are we studying?

We are studying how we may improve the support we provide to families whose loved ones die in intensive care. Losing a cherished family member is never easy and can be particularly difficult for families' whose loved one dies after a critical illness. This is especially so during this time of restricted visitation due to the Covid 19 outbreak.

For this study we are interested in

- Exploring whether photographs of patients hands taken before death may be helpful to bereaved families.
- Interviewing bereaved families approximately two months after the death of their loved one to learn more about their experiences, feelings and suggestions.

The knowledge we gain from this study will be used to improve the support we provide to families who suffer bereavement after critical illness.

What does taking part involve?

This study involves two parts, should you choose to participate in the study, you may participate in both parts or in one part only.

Part 1 - Hand Photographs

We are offering patients who are dying in the intensive care unit or their designated substitute decision maker the option of having the patient's hands photographed before death as a memento. Mementos such as locks of hair and footprints have been shown to help families who have suffered the loss of a child and we would like to find out if they may also help families who lose adult members.

Where patients or their designated substitute decision maker wish to receive a photograph of the patient's hands, these photographs will be taken by a member of the study team and made available to the patient's substitute decision maker either in electronic format or as a hard copy or both.

Should you be interested in participating in the study, you may choose to either

- Receive hand photographs and agree to being interviewed afterwards.
- Not receive hand photographs and agree to being interviewed afterwards.
- Receive hand photographs and not agree to being interviewed afterwards.

Part 2- Interviews

Whether patients or their families choose photographs of the patients hands or not, we would like to interview families whose loved ones died in intensive care. Where families agree, these interviews would take place over the phone with the patients substitute decision maker and a member of the research team, approximately two months after your loved ones passing.

The interview will last approximately 60 minutes and all information shared in the interview is confidential.

The interview will be audio recorded and a transcript made of the recording. This is done to both allow the researcher to focus on their conversation with you and so that we can best capture the information you provide. During the interview the researcher will ask you about your experiences and feelings around the time of your loved ones death and afterwards. We would also like to know if you or your family has any suggestions for how we may better support bereaved families.

If you chose to receive photographs of your loved ones hands, we would also like to know whether and how you found the photographs helpful.

After the interview is complete you will be given the opportunity to review your interview transcript should you wish, so that you may confirm the information you have provided, provide any additional clarification and remove information that you do not want to be included in the study.

Why I have been invited to take part?

We are inviting you to participate because your thoughts, feelings and experiences are valuable to our understanding of bereaved families needs. The information provided will help us to improve the support we provide to families who lose loved ones due to critical illness.

What are the potential benefits and risks?

Information you provide, as part of this study will improve our understanding of bereaved families needs so that we may better support these families. While there are no anticipated risks to taking part, we know that considering and participating in a study during this difficult time is a very individual decision and you should feel under no pressure to participate and you retain the right to withdraw from the study at any time.

What will happen to the data collected?

For the purposes of this study data means any photographs taken, researcher's notes, audio recordings and any email exchanges you may have with the research team. Audio recordings, emails and photographs will be stored on a secure password protected computer. Any written notes will be stored securely in a locked cupboard, in a locked research office at Kingston Health Sciences Centre and or Queens University. Any indentifying information will be removed at the outset. Only members of this study team will have access to all study data and all data collected will only be used for the purposes of this study and its subsequent scientific reports. Any reports of this study will not contain any that any information that may identify you or any member of your family.

Who do I contact for further information?

If you would like any further information or have any questions about this study at any time, please contact Imelda Galvin at Imelda.Galvin@kingstonhsc.ca

‘HANDS OF HUMANITY’ STUDY – CONSENT FORM FOR SEMI STRUCTURED INTERVIEWS

Consent form –

To be completed by the patients designated substitute decision maker only

- I voluntarily agree to participate in the ‘Hands of Humanity’ Study, conducted by Dr. Imelda Galvin and Dr. Christopher Meyer, Critical Care Department, Kingston Health Sciences Centre and Queens University. I understand that the study is designed to gather information about bereaved families experiences and feelings after their loved one dies in intensive care
- I understand that even if I participate now, I can withdraw from the study at any time
- I have had the purpose and nature of the study explained to me and I have had the opportunity to ask questions about the study
- I understand that I may not benefit form the research and that I will not receive any payment for taking part
- I understand that the study may involve being interviewed by a member of the research team and that written notes, audio recordings and transcripts of the interview will be made
- I understand that any information I provide will be treated confidentially and stored securely and any information that identifies me or my family will be removed
- I understand that any reports of this study will not identify me or my family

Participants Name

Participants Signature

Date.....

Research Team Members Name.....

Research Team Members Signature.....

Date.....

‘HANDS OF HUMANITY’ STUDY – CONSENT FORM FOR HAND PHOTOGRAPHY

To be completed by patient or patients designated substitute decision maker only

Where the patient is able to provide his or her own consent

- I voluntarily give my consent to having my hands photographed and the photographs given to my family substitute decision maker as a memento.

Where the patient is unable to provide his or her own consent

- I voluntarily give my consent to have (patients name) hands photographed and the photographs given me as a memento
- I understand that the ‘Hands of Humanity’ study team may keep de identified electronic and or hard copies of any hand photographs taken.
- I understand that any copies of these hand photographs kept by the ‘Hands of Humanity’ study team will be treated confidentially and stored securely and any information that identifies me or my family will be removed.
- I understand that the ‘Hands of Humanity’ study team may use de -identified copies of these hand photographs in scientific reports that arise from this study including medical publications, including medical journals, textbooks, and electronic publications.

Participants Name

Participants Signature

Date.....

Research Team Members Name.....

Research Team Members Signature.....

Date.....

ITEM 2 - 'HANDS OF HUMANITY' STUDY – INTERVIEW GUIDE

Thank you for taking part in this study and agreeing to speak with us today. Losing a family member is always difficult and its especially so during the Covid 19 outbreak when visiting is restricted. We want to offer the best support possible to families who lose loved ones at this difficult time.

We started the 'Hands of Humanity' project to try and provide some comfort to families of people who pass away in intensive care. Whether you chose to receive photographs of your (father/mother/sons etc.) hands not, we would greatly appreciate you sharing with us your thoughts and feelings about the option of receiving these photographs and your experiences surrounding your loved ones death. The information your provide will help us to help other families who lose their loved ones in similar circumstances.

As I ask you these questions I understand that some of them may be upsetting, if you need to take a break at any time or don't wish to answer a particular question, please let me know. Where you can, please describe your thoughts and feelings in as much detail as possible.

1. First, may I ask you to tell me some details about your self? Relationship to patient, age, gender, ethnicity, spiritual beliefs
2. Before your loved one passed away did your hear about the option of having your loved ones hands photographed?
3. How did you feel when you heard about it, did you decide to receive hand photographs or not? if so why/ why not ?

For Families members who decided to receive hand photographs

Now I would like to ask you some questions about those photographs

1. What affect did having your (fathers/mothers /sons etc.) hands photographed have on your experience of his /her death?
2. Have you found the photographs helpful or unhelpful to you during this difficult time?
3. How have you used the photographs (e.g. put them away, looked at them occasionally, displayed them at home, shared them with family or friends, posted them on social media, used them in a memorial service etc.)?
4. Do the photographs have a special meaning or significance for you?
5. For you, what stories do the photographs tell/not tell?
6. Is there anything else about your experience of having these photographs taken or your thoughts and feelings about the photographs that you would like us to know?
7. Do you think the hands of humanity project should continue? Why /why not?
8. Do you have any suggestions to improve the hands of humanity project?

If it is OK with you I would now like to ask you some questions about your experiences surrounding your loved ones death.

1. As you know at present families cannot visit their loved ones during their time in intensive care (except when they are dying), can you tell me how this affected you and your family? During your loved ones illness and afterwards?
2. As you experienced, a maximum of two family members are currently allowed be physically present when their loved one is dying, can you share with us how this restriction affected you and your family? at the time of his/her death and afterwards.
3. Where you able to be physically present with your loved one when he /she passed away?
4. How many members of your family were able to be there and did other family members participate virtually and if so how? Phone/ conference call /video chat
5. Do you have any suggestions to improve the experience of families whose loved ones die in intensive care?
6. Is there anything else that you would like us to know about your experience of losing a loved in intensive care?
7. How are you and your family coping since your loved ones death? Would you like me to arrange for a spiritual care advisor or social worker to contact you?

For Families members who decided *not* to receive hand photographs

If it is OK with you I would like to ask you some questions about your experiences surrounding your loved ones death

1. As you know at present families cannot visit their loved ones during their time in intensive care (except when they are dying), can you tell me how this affected you and your family? During your loved ones illness and afterwards?
2. As you experienced, a maximum of two family members are currently allowed be physically present when their loved one is dying, can you share with us how this restriction affected you and your family? at the time of his/her death and afterwards.
3. Where you able to be physically present with your loved one when he /she passed away?
4. How many members of your family were able to be there and did other family members participate virtually and if so how? Phone/ conference call /video chat
5. Do you have any suggestions to improve the experience of families whose loved ones die in intensive care?
6. Is there anything else that you would like us to know about your experience of losing a loved in intensive care?
7. How are you and your family coping since your loved ones death? Would you like me to arrange for a spiritual care advisor or social worker to contact you?