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## **Designing for Palliative Care**

### **Information statement for research project participants (online research platform)**

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Thank-you for taking the time to read about our research. You are invited to contribute your ideas about how spaces for palliative care could be designed better for patients, their families and healthcare teams. This forms part of the research project identified above which is being conducted by Rebecca McLaughlan from the School of Architecture and the Built Environment at the University of Newcastle.

#### ***Why is the research being done?***

Dying and losing a loved one are significant and challenging life events. The purpose of the research is to understand whether hospital environments could be designed to better support people through end of life experiences. The interest of this project in understanding how the appearance of hospital environments makes patients, their families and health care teams feel, how they work for people, and what could improve them. Our findings will be used in conference presentations, journal articles and design guidelines that will be used by people who commission and design hospitals.

#### ***Why are you being asked you to participate in the research?***

The project hopes to engage participants who have recently spent time within a palliative care environment (hospice or hospital based), either as a patient, family member, member of a medical team, as well as members of the public who have an interest in palliative care environments.

#### ***If you agree to participate, you will be asked to contribute your opinions to the project website.***

You are invited to respond to the photographs and stories uploaded on the project website or post your own photographs and stories about your experiences of palliative care environments. You can send your responses to the researcher confidentially or share them for others to read.

#### ***What choice do you have?***

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Posting information to the researcher is taken as confirming your consent. If you chose to share your post but change your mind later, just email the researcher and this will be removed from public view. Owing to the sensitivity of this topic, only posts that comply fully with guidelines for posting can be shared, you will find these guidelines under the "About the project" tab on the project website. Withdrawing your post will not affect any relationships you have with the researcher, any associated medical institutions or the University of Newcastle.

#### ***What are the risks and benefits of participating?***

This project asks participants to speak specifically about their architectural perceptions and preferences, no personal information will be asked of you and you can withdraw your information at any time. In order to protect the confidentiality and wellbeing of participants, their family members and healthcare professionals, posts will not be released for public view if the following details are visible or listed within the posts that are shared publicly:

Written posts that list the names of the patient, family or staff member/s, or the names and/ or specific locations of a hospital.

Photographs with people, hospital logos or names in them. If you'd really like to share a photograph publicly that has a person in it, you can blur the appearance of the person within the photograph so they cannot be recognised.

Content or language that may be considered disturbing to others. The researcher is obligated to take a conservative view of this. However, even if your post cannot be made public it will still be highly valued by the researcher and used to inform the research project.

Content that may be considered defamatory towards individuals or organisations.

All information provided to the researcher, whether cleared for sharing on this website or not, will be valued and used to inform the broader research project. The data you provide may be cited within conference presentations and journal articles. This will be made anonymous by a code so that any user names that may be traceable back to individuals are concealed.

Given that these steps will be taken, there is no foreseeable risk to your engagement with the online research platform.

This project seeks to identify architectural solutions capable of encouraging early engagement with palliative care services; supporting better communication during end-of-life events; and supporting safe and efficient care within palliative care environments. Patients who fail to engage with palliative care can experience higher levels of pain, anxiety and depression than those who engage early with this medical service. Family members are often engaged as informal providers of palliative care and this responsibility can result in negative consequences to wellbeing. Some studies also suggest that healthcare workers engaged in end-of-life care have a higher susceptibility to work-related stresses than those employed in other specialties. Greater research investment in the design of palliative care facilities could provide far-reaching benefits for patients, their families and medical teams.

### ***How will your privacy be protected?***

When submitting posts participants are asked to nominate a user name that does not reflect their own name or other user names they frequently use. This step maintains confidentiality for all participants.

This website will remain active and publicly accessible for the duration of this project (anticipated end date: 20 December 2022). Following closure of the website this data will be kept securely in the School of Architecture and Built Environment for five years from the end date of the project, on the University of Newcastle's ownCloud secure server, after which time it will be destroyed.

### ***How will the results be shared with you?***

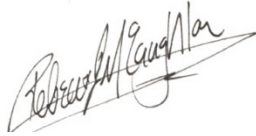
The project website will be updated (details below) with news of our publications from this research. Where not prohibited by copyright, journal articles will be uploaded to the project website for you to access and, where this is not possible, you are welcome to email the researcher directly to request a copy.

### ***What do you need to do to participate?***

If you would like to participate, please log onto the project website: [www.palliativecare.design](http://www.palliativecare.design)

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher.

Thank you for considering this invitation.



Dr Rebecca McLaughlan  
Lecturer in Architecture & DECRA Research Fellow

### ***Complaints about this research***

This project has been approved by the University's Human Research Ethics Committee, Approval No. H2019-056. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).