Fellowship proposal May 2020

Learning for improvement from COVID-19 intensive care patient experiences

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1 Background

COVID-19 is a new coronavirus that, according to the latest evidence, emerged in China in late 2019 and has since spread rapidly worldwide. The World Health Organization declared a Public Health Emergency of International Concern on 30th January 2020. COVID-19 affects different people in different ways. While some experience mild disease and never require hospitalisation, others develop serious illness or critical symptoms. Pneumonia is the most common form of illness for those acutely affected by COVID-19 as the disease prevents the normal passage of oxygen from the lungs into the bloodstream. People who become seriously ill with COVID-19 may be cared for in intensive care units (ICU). On current estimates, around half of these patients will survive ICU.

The long-term impacts of COVID-19 on patients and family members remains unknown, but research on ICU recovery indicates that people may suffer a range of short, medium and long-term physical and emotional consequences, including post-ICU syndrome, post-traumatic stress disorder and multiple other effects. The COVID-19 pandemic and the associated changes in care may result in a distinctive set experiences and outcomes. For example, in normal times, family members have a vital role in supporting patients and improving the ICU experiences of their relatives. However, the requirements of social distancing have resulted in restrictions on the presence of family members in ICUs, with patients often interacting only with healthcare staff who are wearing personal protective equipment.

Patient narratives can convey individual experiences of illness and healthcare that complement and augment epidemiological and public health evidence. Listening to patient stories has long been a core element of clinical medicine. The use of narrative research, as collected through rigorous patient experience (PEx) research, has become increasingly well-established as a means of understanding and reporting on the social and cultural contexts of health and health care. However, how these experiences can be used to inform improvement strategies for healthcare remains less well-developed.

1.1 Healthtalk

One important resource in the PEx field is Healthtalk.org, a freely available website that has been publishing rigorously researched patient experiences online in the United Kingdom for the last 20 years. The content is based on interviews with patients and others that are conducted using rigorous qualitative methods. Summaries of the interviews are then produced, together with audio, video or text extracts, and published on the website. Now including thousands of narratives covering over 110 different health conditions, Healthtalk is important in helping people understand what it is like to have a particular condition, in preparing individuals and their family and friends for what’s ahead, in informing decisions about treatment options, and in guiding practical actions. As well as its important role in improving the experiences of patients and families, Healthtalk has aims to support healthcare professionals in providing patient-centered care and to promote better communication between patients and professionals. It has a strong educational focus and is widely used for teaching and training, and is used as a basis of high quality academic publications. Increasingly, Healthtalk is supporting use of the resource for service improvement, for example using a model of “catalyst films” aimed at getting people,
patients, families and NHS staff talking together about how they can jointly improve people’s experiences using methods such as experience-based co-design.

Healthtalk.org is run by the DIPEX Charity, which was founded in partnership with the Health Experiences Research Group (HERG) at the University of Oxford. The DIPEX International (DI) collaboration now includes 13 (HIC) countries conducting research using the same methods and published on sister sites (www.dipexinternational.org).

Two previous Healthtalk projects conducted by HERG and funded by the Intensive Care National Audit and Research Centre (ICNARC) have captured the experiences of 40 patients and 38 family members’ experiences of intensive care. Published in 2006, they offer valuable insights, but the particular experiences of being critically ill with COVID-19 in the midst of a pandemic requires further investigation. How such experiences can then be used to inform improvements in care for people who are or have been critically ill during a pandemic also needs study.

2 Fellowship award

THIS Institute wishes to make an award of a fellowship to an individual to be based at their own university to lead a project to:

- Capture the experiences of people who have been critically ill with COVID-19 and been cared for in an ICU and those of family members of survivors and non-survivors, using Healthtalk methods (adapted for pandemic conditions);
- Provide enduring resource and support to patients, carers, and other stakeholders on Healthtalk.org. Accessible summaries (approx. 25) of the most important aspects of people’s experiences should be prepared for dissemination on the Healthtalk website, illustrated with selected extracts from the interviews. These will provide the basis for a new section at www.healthtalk.org to improve public and professional understanding of people’s experiences of critical illness with COVID-19.
- Explore and evaluate how the perspectives and priorities of patients themselves can provide a basis for co-design of care and service models for care on ICU and for support/follow-up, as well as generating learning from response to COVID-19 to enhance planning for future pandemics.

The fellow will work collaboratively with Lisa Hinton, Senior Research Associate at THIS Institute, (and former Director of Applied Research at HERG), and with Ruth Sanders, Research Delivery Project Manager at HERG and the DIPEX charity, in the delivery of the project. For this purpose, a collaboration agreement between the fellow’s institution and the Universities of Cambridge and Oxford will be required. THIS Institute will initiate the process to prepare this agreement when the fellowship has been awarded and accepted formally.
3 Project requirements

1. The fellow should establish a suitable advisory group for the project, which should include patient and carer representation, representation from HERG and relevant other stakeholders (e.g. charities, professional groups). The support of THIS Institute will be available to facilitate this.

2. The fellow will be expected to develop a high quality protocol. It should:
   a. Be grounded in the relevant literature on patient narratives, ICU experiences, and post-ICU experiences.
   b. Clearly articulate the aims of the project, which should include:
      i. capturing the experiences and priorities of people with COVID-19 who have been cared for in ICU, as well as their family members
      ii. developing an approach to identifying and evaluating how those experiences might be used to co-design improvement strategies both for care in ICU and post-ICU
   c. Identify collaborators and partners who may be needed to deliver on the project goals, with the support of THIS Institute.
   d. Specify a sound study design that uses Healthtalk methods, adapted for pandemic conditions (e.g. it is likely interviews will need to be conducted remotely).
   e. Identify a sensitive and feasible plan for recruitment of around 50-60 participants, including patients with COVID-19 who have been cared for in ICU and relatives of survivors and non-survivors. Where appropriate, this is likely to involve working in partnership with relevant NHS organisations, charities and other bodies, supported where appropriate by THIS Institute.
   f. Identify a plan for obtaining consent and conducting and recording narrative interviews with patients to standards and formats agreed with HERG, using well-developed qualitative interviewing skills.
   g. Identify a plan for conducting appropriate qualitative analysis of the interview data and preparing the results for submission to peer-reviewed academic journals.
   h. Identify a plan for how the results of the study will be used to inform improvement strategies for caring for people with COVID-19 both on ICU and post-ICU, with a particular emphasis on co-design. The protocol should draw on relevant literatures about methods for improvement and co-production and should explain how the work will advance the field of using patient experiences, participatory research and co-design to improve care.

3. The fellow should work collaboratively with HERG and the DIPEX Charity to prepare a series of lay topic summaries for publication online and to prepare open access resources for Healthtalk.
4 Fellow requirements

Applicants for this fellowship should be experienced and skilled qualitative researchers who can lead the project independently while sustaining excellent relationships with collaborators, patients and families, clinicians, and wider health service stakeholders. Applicants should have a PhD in either social science, health services research, health psychology or a related subject or, exceptionally, equivalent postgraduate research experience. Applicants should have a good publications record for stage of career, including peer-reviewed qualitative research publications, and demonstrate interest in how PEx might be used to inform the design and implementation of improvement strategies in healthcare.

This fellowship is suitable for applicants who are currently in post at UK universities who are available to work as soon as possible on this award. The successful applicant will remain employed by their own university. These fellowships may be especially suitable for academic or research staff who would benefit from replacement salary while their current research is paused.

The appointed fellow will be offered a professional development programme which will be discussed on award and customised to the specifics of the fellow’s needs, commitments, and fellowship duration. The programme may include, for example, membership of a learning set, coaching, and/or mentoring. Full engagement with the agreed programme will be expected.

5 Budget

The award will include salary costs (at the agreed proportion of FTE) and research expenses directly relevant to the project up to a maximum of £120K.

Expenses may include, for example, transcribing, conference fees, fees for open access publications, small items of equipment (e.g. encrypted recorder); vouchers for participants; and expenses associated with the Advisory Group.

A separate payment will be made to HERG and the DIPEx Charity to cover their expenses and will not form part of the fellowship award.

This fellowship should be completed in 18 months, or up to a maximum of 24 months if part-time. It is expected that the fellowship will begin during Summer 2020.

The appointed fellow should be in post at their own university at time of application and is intended to remain employed by that university for the duration of the fellowship.
5.1 Timeline based on 18 months full-time (may be adjusted for a part-time award up to 24 months)

(Based on one researcher conducting interviews, using the existing ethics approval process for Healthtalk)

<table>
<thead>
<tr>
<th>Month 1-2</th>
<th>Training and setting up advisory panel, writing protocol, collaboration agreement</th>
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<tbody>
<tr>
<td>Month 1-8</td>
<td>Field review, recruitment, interviewing, checking transcripts, checking copyright and time-coding interviews.</td>
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<tr>
<td>Month 3</td>
<td>The advisory panel is usually held after 10/12 interviews.</td>
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<td>Month 7 &amp; 8</td>
<td>Analysis of data, data entry</td>
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<tr>
<td>Month 9 &amp; 10</td>
<td>Writing and preparing topic summaries</td>
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<tr>
<td>Month 10</td>
<td>Summaries reviewed by Advisory panel</td>
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<td>Month 11</td>
<td>Final delivery of topic summaries etc. to website team</td>
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<tr>
<td>Month 11-12</td>
<td>Website production and development</td>
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<tr>
<td>Month 13-18</td>
<td>EBCD and development of patient and family support/follow up resources/recommendations. Publications and dissemination</td>
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