Critical Care Futures

About the project

Critical Care Futures was a public engagement project that creatively involved a range of professional and public ICU stakeholders in a dialogue about the boundaries between research and care. Its goal was to influence our approach to critical care research in the future and to create evidence that supports the use of creative methods of public engagement in health research.

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Who was involved?

Core team:
Dr Annemarie Docherty (University of Edinburgh and NHS Lothian), Dr Catherine Montgomery (University of Edinburgh), Dr Corrienne McCulloch (NHS Lothian), Santini Basra (Andthen), Lizzie Abernethy (Andthen), Freyja Harris (Andthen)

Co-design support from:
Jean Antonelli (University of Edinburgh), Dr Monika Beatty (NHS Lothian), Joanne Mair (University of Edinburgh), Goutam Das (PPI Representative)
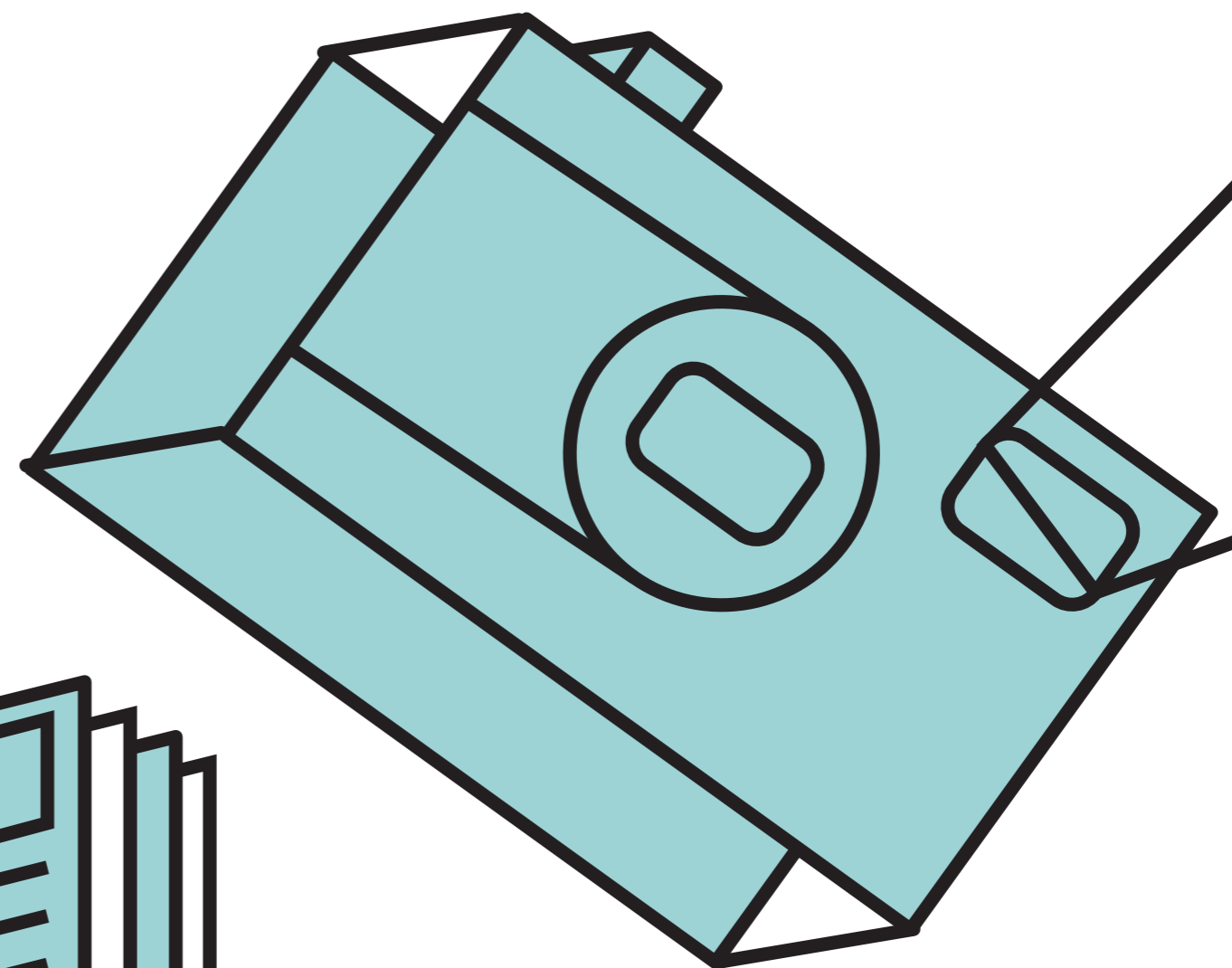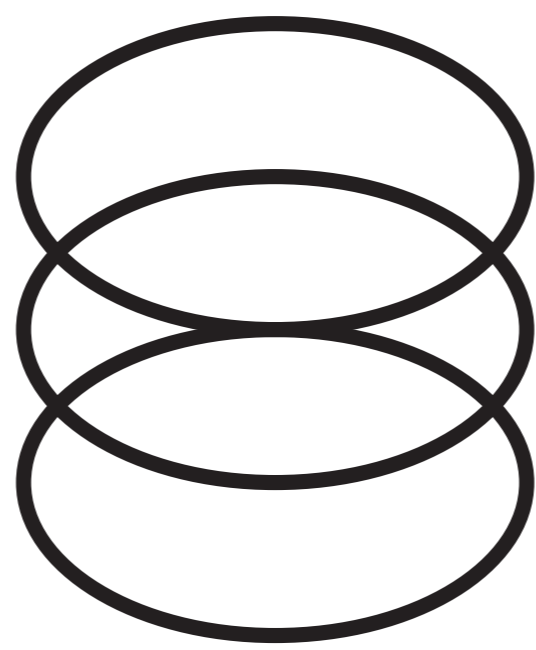
Cultural Probes — a creative approach to engagement

Our project aimed to change the way researchers and research participants interact, using a design research tool called 'cultural probes.' These probes were sent to patients, relatives, clinicians, researchers, and research governance staff and contained tasks such as taking photos, creating maps, writing creatively, and making postcards. By completing these tasks individually, they were encouraged to observe, reflect, and share their experiences, values, and beliefs, before coming together and discussing their results in a group setting. This allowed us to explore new possibilities and catalyse conversations to create space for new thinking about critical care research.

What did we create?

The project surfaced different perspectives and ideas from the groups involved. We used these to create a set of principles for research in critical care, based on the views of those who participated in the project. This focused on their thoughts about data, consent, and putting the patient first. We also produced a range of artefacts, printed on which are some of the more provocative questions or conversations that came out of this work. These have been placed around you. For example, you might find yourself signing a form with a pen that makes you think about what 'informed' consent really means. Or, you might sip your tea from a mug that suggests new ways for patients and researchers to exchange value.
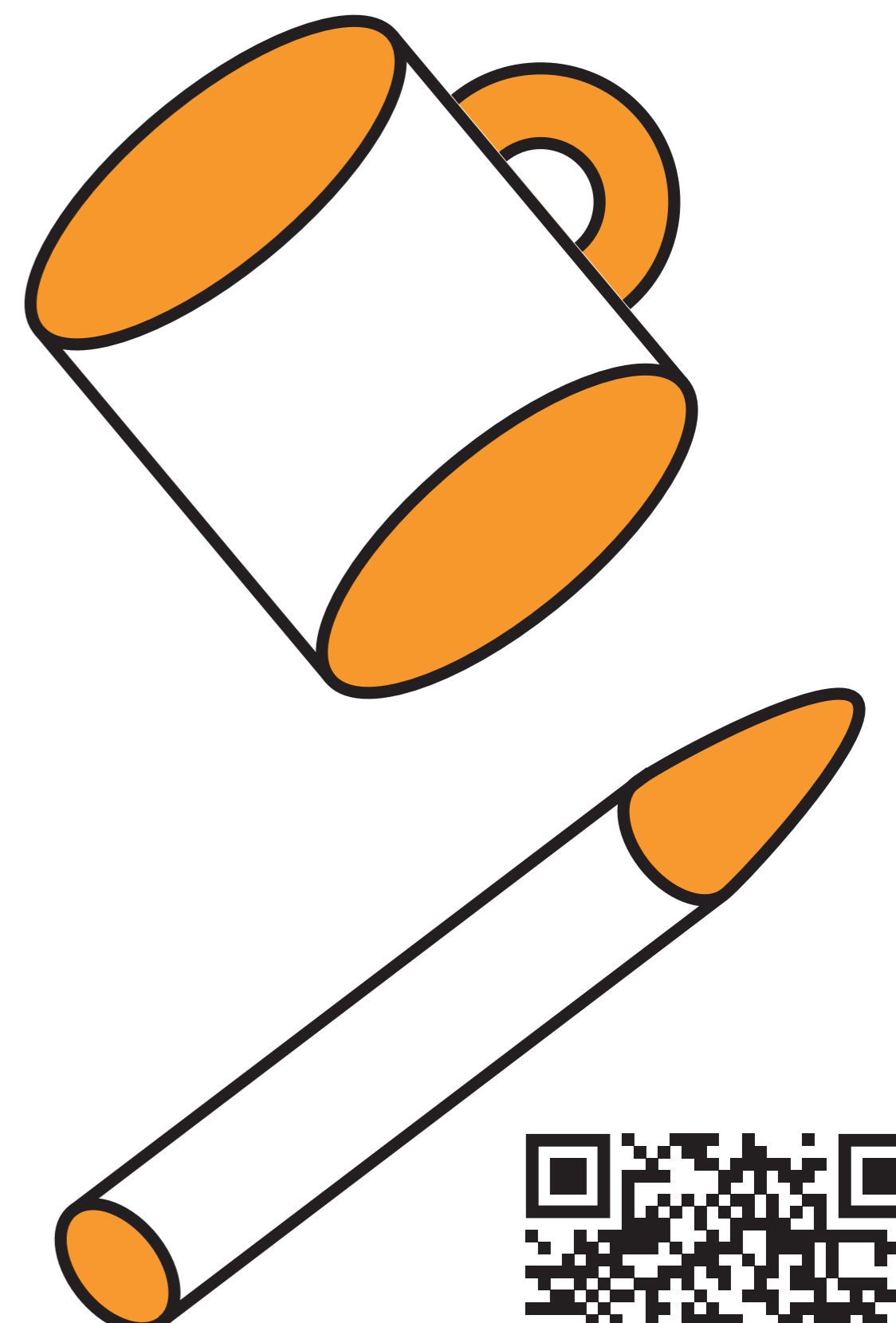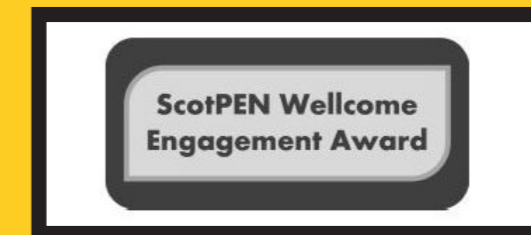
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Principles for Critical Care Research

These principles are one of the key outcomes of the public engagement activities involved in the Critical Care Futures project. They were distilled from the content shared in the cultural probes and were shaped alongside all those who participated in the project during a collaborative, and highly interdisciplinary workshop.

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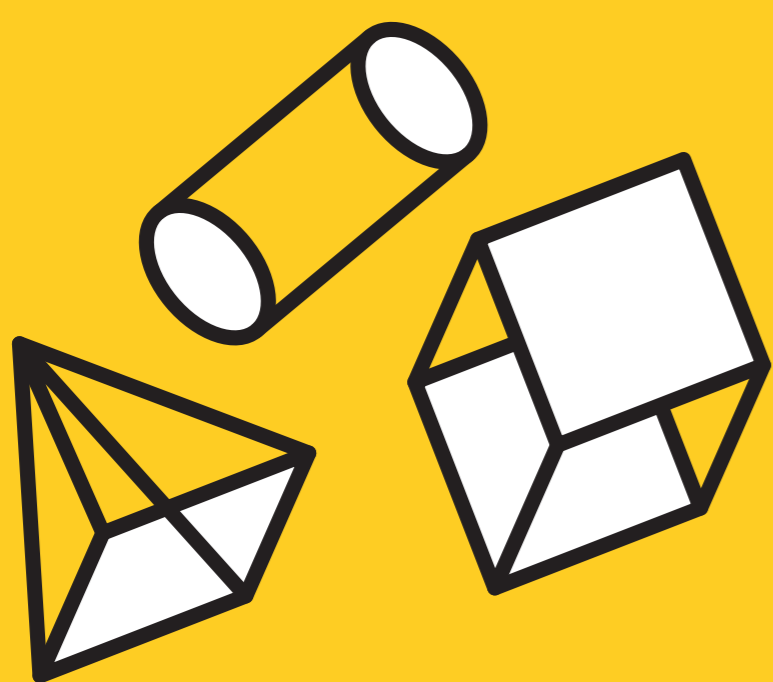
Be clear about what's meant when we say 'data'

The word 'data' describes a vast array of information, which can make discussing it in general terms challenging. This vague language can make it difficult to achieve mutual understanding and talk about preferences for gathering, using, accessing, and storing data. To support meaningful conversations about the treatment of data, particularly with patients and their families, it is important to create clear taxonomies that classify different forms of data.
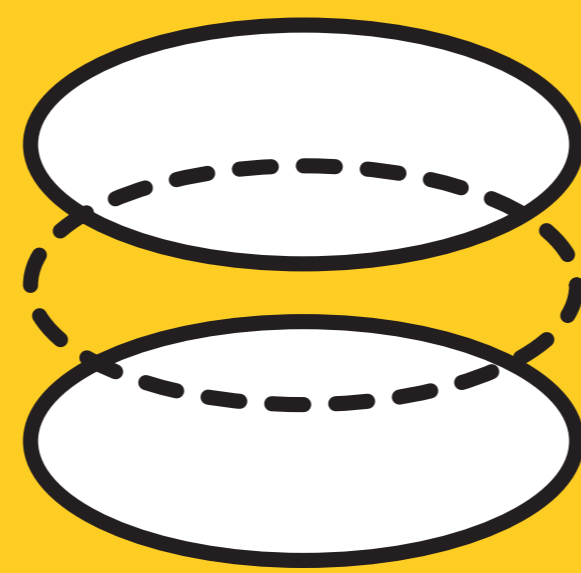

Be transparent about how data are used

We need mechanisms which support both patients and clinicians to have more transparent conversations about how the patient's data are being used. Transparency can be supported through interventions both within and outside an ICU setting; while we need to further develop internal best practices around how and when to share information with patients and next of kin, we also need to support transparency by making broader efforts to develop the public's basic level of understanding of data practices and infrastructures.
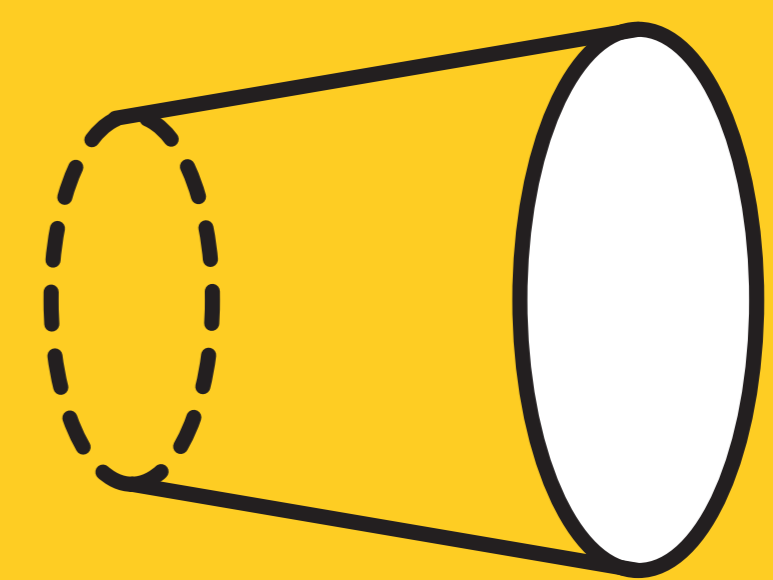
Form an identity around critical care research

There are relatively low levels of public awareness around critical care research as opposed to other forms of healthcare research (such as cancer or COVID-19 research). The public is unclear on what is involved, and why or how critical care research can deliver improved outcomes for them. Critical care research needs to develop a distinct identity and clear messaging around its purpose. One approach may be to reframe critical care research as an opportunity that enables a valuable exchange—one where the healthcare system can use patients' data to improve care, and the public can give back to the system by sharing their data.
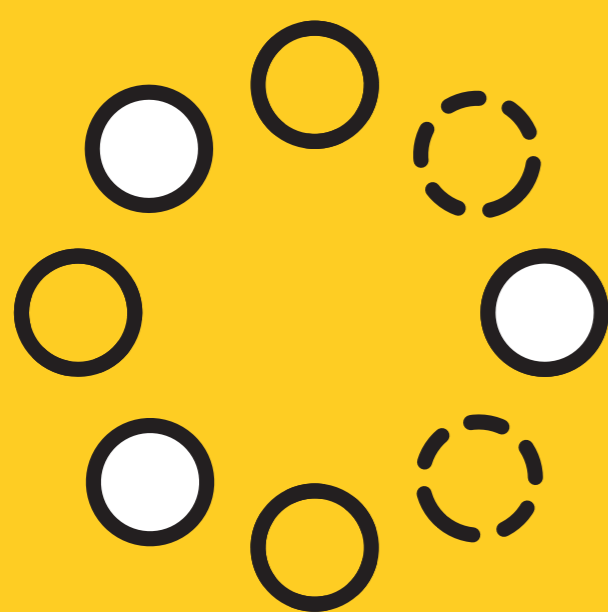

Explore models which ask for consent at a different time

Current consent models used in critical care research are uncomfortable. They require practitioners to ask for consent at inappropriate times, which puts an unnecessary burden on patients or their next of kin, who are asked to read through lengthy forms and understand complex concepts during a difficult time when this is not their primary concern. It is important to consider alternative models of consent, such as in stages or at different points in a patient's journey.

Place the patient at the center of the consent process

The current model for consent tends to focus more on the rules and ways of our existing systems than on helping patients understand what's happening. Sometimes it's hard to tell whether patients are truly 'informed' and really understand what they're agreeing to. We need to develop an approach to consent that places the patient at its heart. This approach should be able to accommodate different individual circumstances, and should sensitively support patients and next of kin along the various steps of the journey that are required for them to become 'informed.'
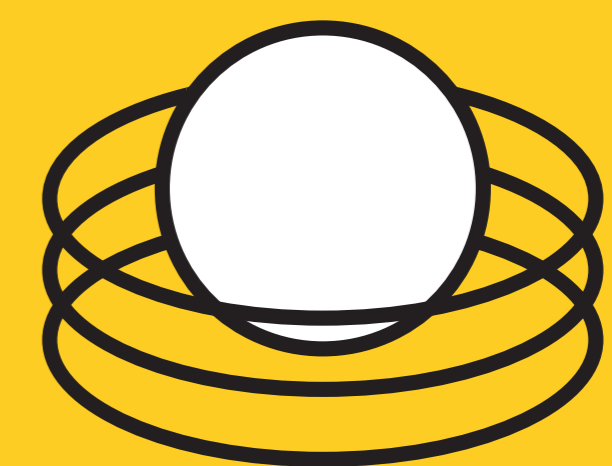
Create a research environment which cares for the patient

A research environment needs to care for the patient. This means it needs to be considerate of all other care and support the patient may be receiving, smoothly integrating with the clinical team. A caring research environment also pays close attention to communication and maintaining a sense of safety; it encourages anything that helps a patient feel a sense of familiarity, keeps their family up to date, and ensures good visibility of staff, and of the outcome of the study.