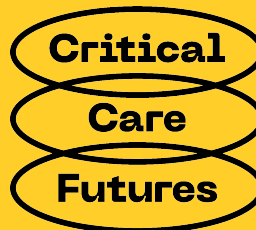


# Critical Care Futures

Insight report  
March 2023

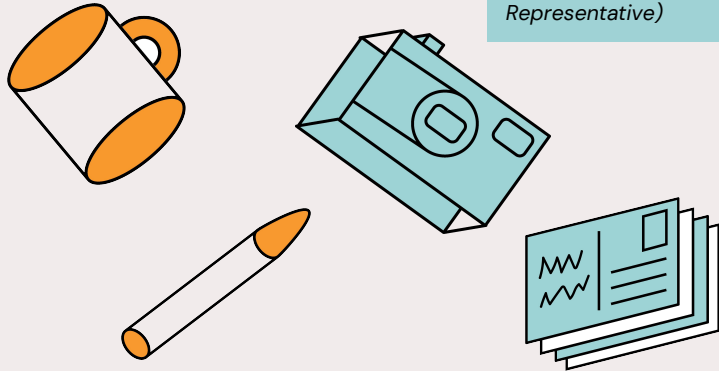


*Critical Care Futures was funded by the Scottish Public Engagement Network (ScotPEN) through the ScotPEN Wellcome Engagement Award. Grant reference: 217078/Z/19/Z.*

# Summary

## 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.



## 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 ICU survivors, 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 alternative possibilities and catalyse conversations to create space for new thinking about critical care research.

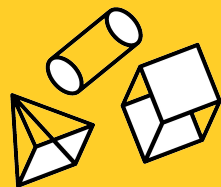
## What did we create?

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 will be installed in critical care units, with the intent that they will trigger critical thought at key moments. For example a researcher might find themselves signing a form with a pen that makes them think about what 'informed' consent really means. Or, a clinician might sip their tea from a mug that suggests new ways for patients and researchers to exchange value.

## Overview of the principles

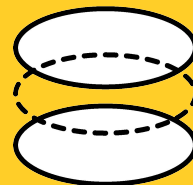
These principles are one of the key outcomes of the public engagement activities involved in the Critical Care Futures project. They were distilled from the content shared in the cultural probes and were shaped alongside all those who participated in the project during a collaborative and highly interdisciplinary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

In this report, we outline the conversations and arguments made throughout the engagement by participants, which feed into these principles.



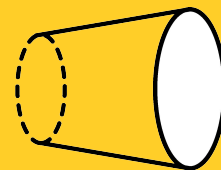
### Be clear about what's meant when we say 'data'

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

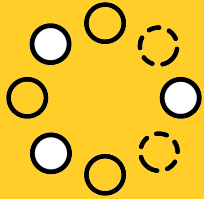
We need mechanisms which support both patients and clinicians to have more transparent conversations about how the patient's data are being used. Transparency can be supported through interventions both within and outside an ICU setting; while we need to further develop internal best practices around 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

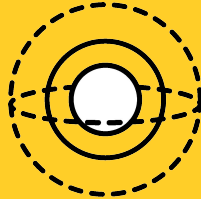
There are relatively low levels of public awareness around critical care research as opposed to other forms of healthcare research (such as cancer or COVID-19 research). The public is unclear on what is involved, and why or how critical care research can deliver improved outcomes for them. Critical care 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.





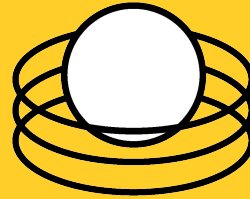
## Explore models which ask for consent at a different time

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 centre 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.

Learn more about the project at [icuheart.org](https://icuheart.org)



**What we did**

# What we did / Cultural probes

**To stimulate discussion amongst survivors, relatives, clinicians, and research governance staff about the future of critical care, we used a design research method known as 'cultural probes.'**

## What are cultural probes?

Cultural probes are a design research method which typically consists of sending small packages that include a series of artefacts which are a vehicle for evocative tasks.

For example, they can take the form of a map, postcard, camera or diary, each consisting of prompts, questions and instructions which encourage participants to record their thoughts and feelings on a specific topic.

## Key characteristics of cultural probes

By nature, they can take many forms, but they do share some key characteristics. They are:

- Self reported
- Flexible
- Open to interpretation
- Encourage imaginative and playful participation

Cultural probes invite participants to reflect on their own experiences in their own way, with the goal of eliciting values, preferences, beliefs and desires. They can catalyse discussion and debate, inspire ideas for future design and allow new ways of looking at an issue.

Take a look at our '[Introduction to Cultural Probes](#)' presentation

## Why did we use cultural probes?

Cultural probes help to disrupt the power imbalance between a researcher and a participant. Giving participants the ability to complete activities in their own time, in their own space and in their own way allows uncertainty and interpretation to reveal insights that may have otherwise been missed by more traditional forms of research.

Probes are also a useful tool within a co-design approach. They help researchers to understand and overcome cultural boundaries and bring diverse perspectives into a design process, in our case for co-producing principles for the future of the critical care research.

Read our blog on '[Cultural probes for public engagement](#)'

# What we did / Who we engaged

This project engaged **19 participants** who represented **5 key groups** connected with critical care research.

The key groups were:

- ICU survivors
- ICU patients' relatives
- ICU clinicians
- ICU researchers
- Ethics committee members and governance staff

*Several of our participants sat across multiple categories.*

## Participant groups

<b>Survivors</b>	● ● ● ● ● ● ● ●
<b>Relatives</b>	● ● ● ●
<b>Clinicians</b>	● ● ● ● ● ●
<b>Researchers</b>	● ● ● ●
<b>Ethics committee members / Governance staff</b>	● ● ● ●







*This visualisation shows the groups that participants identified with. Participants were able to identify as part of multiple groups.*

# What we did / Project process

## Co-designing cultural probes

Throughout this process, we collaborated with a group of 'co-designers', who represented the project's aforementioned key groups.

These co-designers worked alongside the core project team to generate initial ideas, test and refine the cultural probes.

Subsequently, this group helped the core project team to interpret insights and stimulate conversations in the workshop debrief sessions, where principles for the future of critical care research were co-produced.

Read our blog on ['Co-designing cultural probes.'](#)

1

### Probe co-design session

This involved 4 co-designers and 5 members of the research team over a 2 hour creative workshop.

2

### Probes pilot

Our 4 co-designers piloted the probes to ensure they were effective and easy to understand.

3

### Probes study

The refined probes were sent to 20 participants to be completed over a 4 week period.

4

### Debrief workshop

13 participants, and 3 of the co-designers joined us to discuss key themes and create 6 principles. Other participants were debriefed individually.

5

### Refined principles, and public facing outputs

The 6 principles for the future of research in critical care were further refined, alongside a series of artefacts aimed at engaging the public further in key project themes.

## The cultural probe package contained:

### **Instructions:**

Information on how to complete the tasks, how long they would take and a return envelope.

### **Warm Up Activity:**

Participants imagined the ICU as a famous character, to get into a creative headspace.

### **ICU Guestbook:**

A writing task asking participants to leave fictional reviews of good and bad ICU experiences.

### **Photo study:**

A challenge to take photos of things people would like to take with them into ICU.

### **Ballot Slip:**

A task to vote for different candidates who have varying points of view around sharing data and consent.

### **Consent Postcard:**

A challenge to produce a postcard about an ideal consent process in critical care.

### **Data Island:**

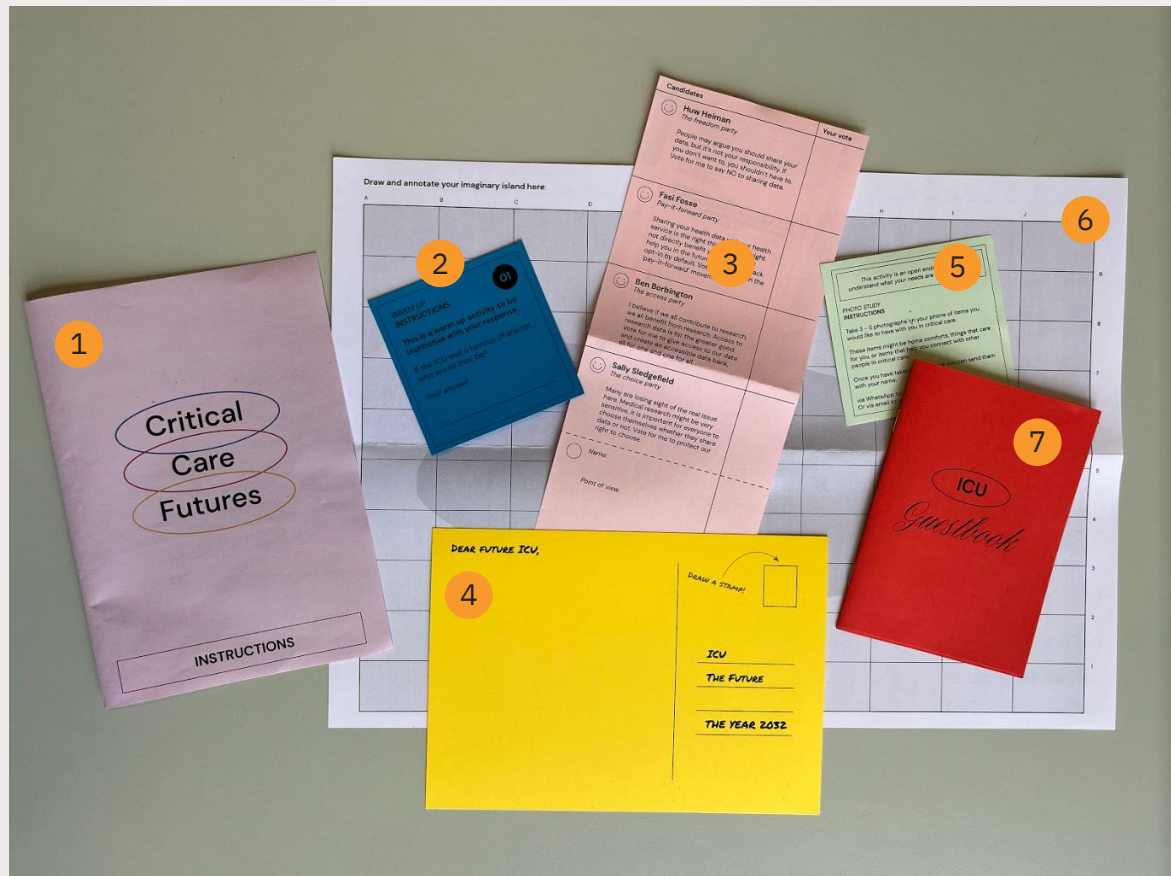
An activity to draw an island that represents how you would like medical data to be handled.

# What we did

## Cultural probe package

- 1 Instructions
- 2 Warm up activity
- 3 Ballot Slip
- 4 Consent Postcard
- 5 Photo activity
- 6 Data Island
- 7 ICU Guestbook

[Download PDF copies of the cultural probes here](#)



# Principles and Provocations

# Principles and Provocations / Introduction

This section of the report is divided into 6 principles. For each principle, we outline the key discussions, themes, and provocations which emerged from the cultural probes and debrief workshop.

There are a few important points to consider when reading this section of the report. Firstly, the responses to the cultural probes and the subsequent debrief discussions were dynamic and non-linear, so ideas and opinions may conflict with one another.

Secondly, some of the cultural probe responses may be more reflective of the current systems in place, rather than aspirational responses of what could exist. For example, many of the consent postcards are tied to existing ways of thinking about consent, and do not explore consent beyond its current regulatory framing. These instances can in themselves be considered as starting points for reflection.



Thirdly, the tone of the cultural probe responses vary depending on the activity. Some activities explicitly pushed participants towards using metaphor and analogies to capture their thoughts (e.g. Warm Up activity

and Data Island), while others, which were left more open (e.g. the Consent Postcard and ICU Guestbook), typically elicited more literal responses, tied to the current realities and experiences in critical care.





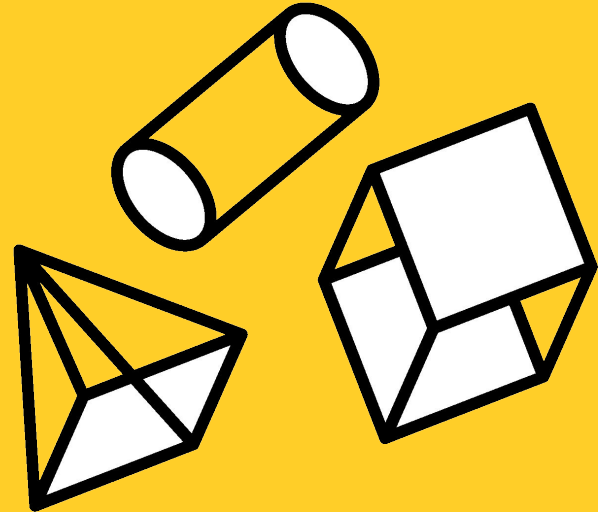
Warm up activity asking participants "If the ICU was a famous character who would they be?"

## Principle #1

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

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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.



## Provocation

## Does everyone mean the same thing when they say 'data'?

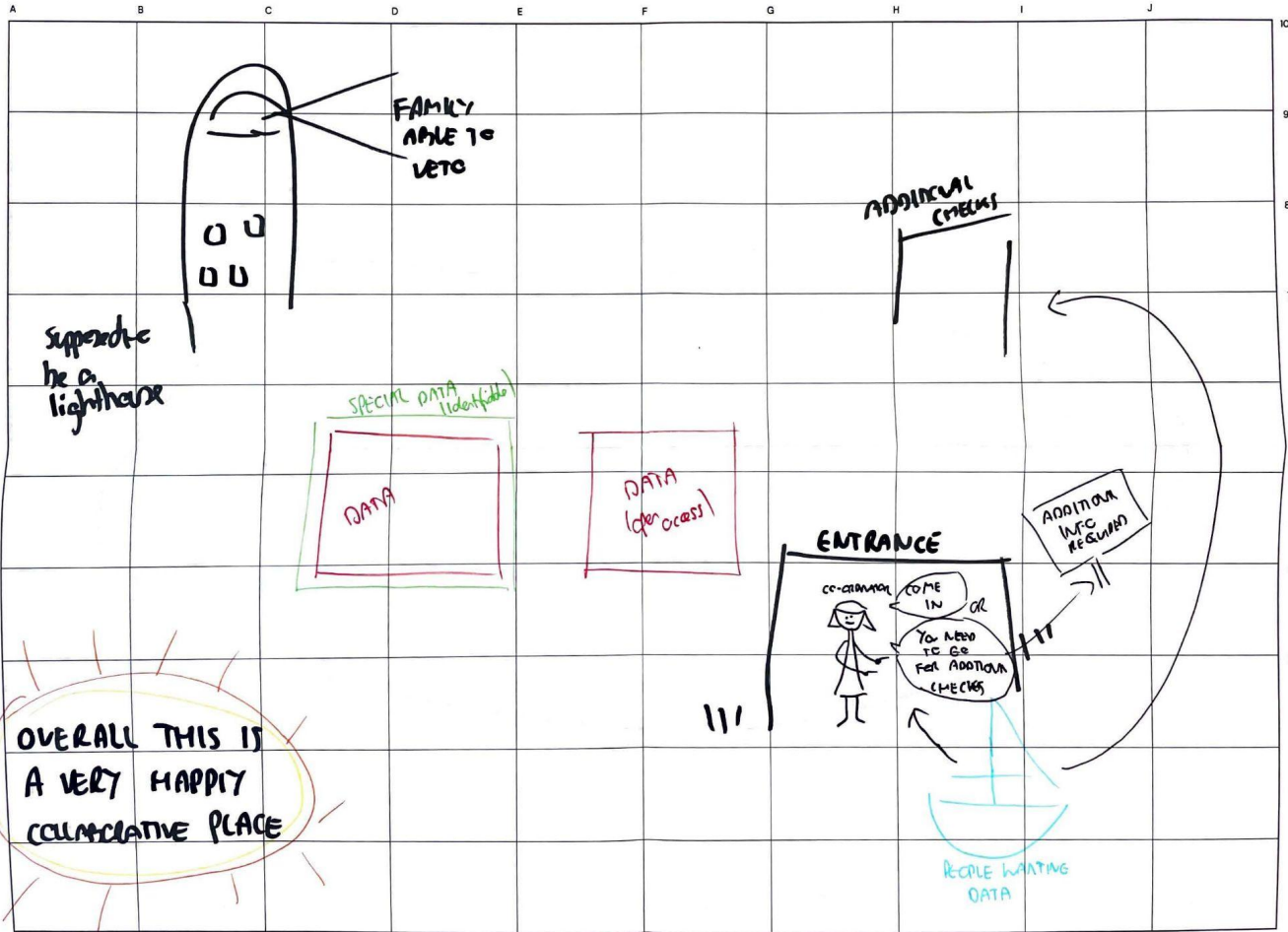
Different groups and individuals had different interpretations of what was being referred to when the term 'data' was used. This rift was particularly apparent between survivors and clinicians, where different language was being used. For instance, survivors and family members didn't typically use specific language around data in their probes, while clinicians and other healthcare practitioners used distinct classifications: 'personal data', 'routine data', 'identifiable data' and so on. However, even across medical practitioners there weren't clear terms that were consistently used, beyond 'sensitive data' and 'anonymised data,' perhaps pointing towards an opportunity to explore how to clarify data-related terminology to improve shared understanding.

## Debrief Discussion Summaries

One clinician shared a story about a patient who asked to withdraw their consent, and in the conversations that occurred as part of the process of withdrawal revealed much more information than was initially collected. The clinician saw this as evidence of a misunderstanding on the patient's part of what 'data' actually is.

In instances during probe debriefs, it was clear that the term data was being interpreted differently by different individuals – for instance in one conversation, a clinician was using the term 'data' to refer to 'routine data,' but a patient was mis-understanding the conversation and felt they were referring to 'personal data', while another patient couldn't understand what was meant by data at all.

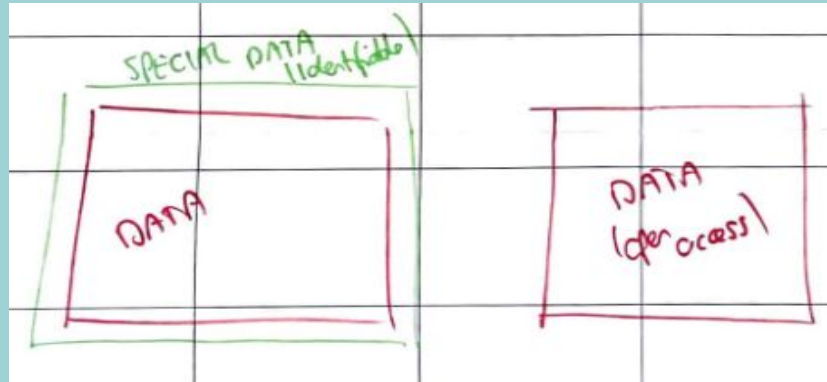
Draw and annotate your imaginary island here.



## Provocation

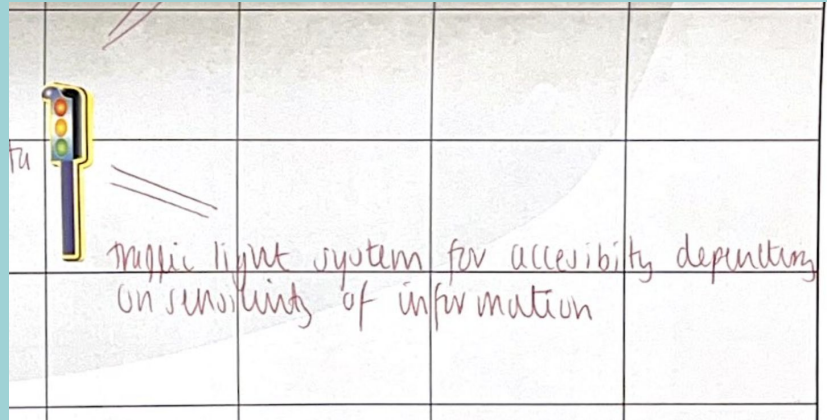
## What should constitute 'green light data'?

Some participants explored ways of segmenting data in their data island. In the same way that there are different models of consent for different types of data, or data with different risk profiles, they suggested different methods of accessing these forms of data, with simpler mechanisms for accessing 'low risk data' and higher protections for 'special data' or 'sensitive data'. Both in the probes and in debrief conversations afterwards, 'low' and 'high' risk data were discussed in metaphorical terms. There was no clear consensus on which specific forms of data would fall into these categories, but there was an acknowledgement across the group that it made sense to explore how such segmentation might happen, for instance by exploring what might constitute 'red light', 'orange light', or 'green light' forms of data.



**Left:** A data island illustrating different zones for types of data – special, identifiable data is treated differently to other data.

*Clinician, Extract from Data Island*



**Left:** A data island with a traffic light system which labels different datasets based on sensitivity and corresponding access requirements.

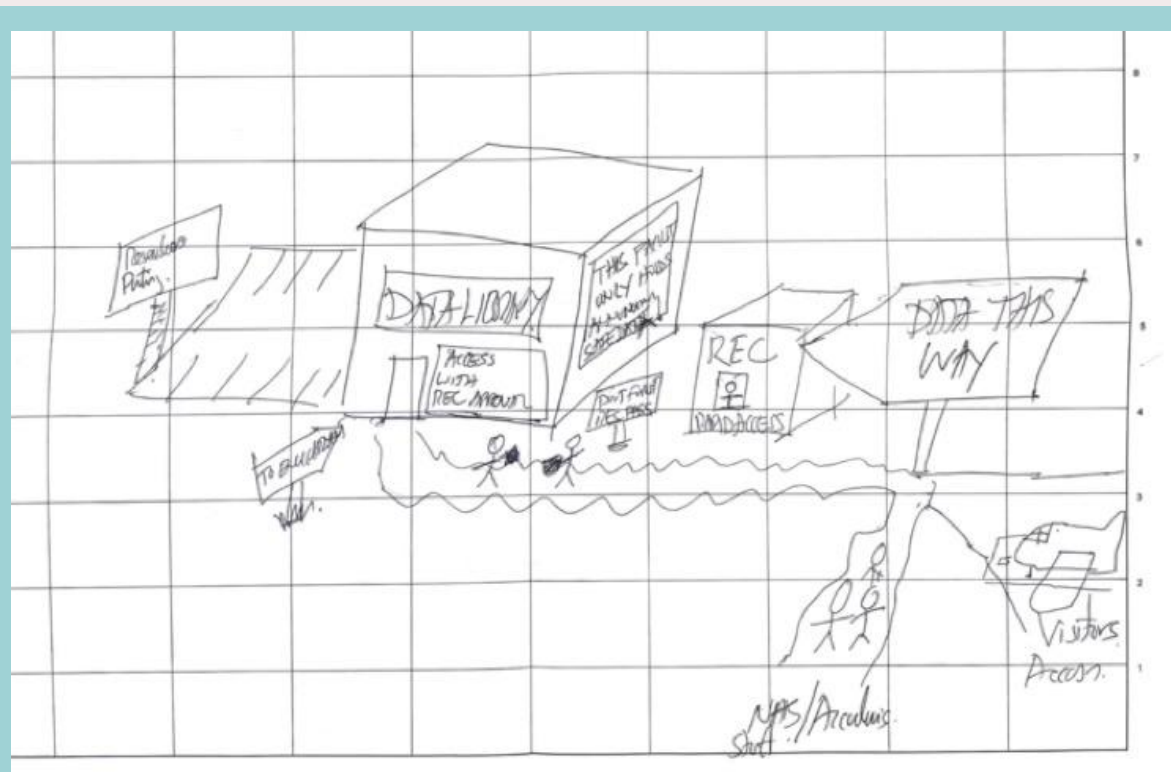
*Clinician, Extract from Data Island*



## Provocation

## What if accessing patient data was like going to the library?

Several data islands depict various routes or options for accessing patient data — for instance suggesting that open, or rapid forms of access could be available for ‘low risk’ data, while more extensive processes could be in place for ‘high risk’ data. Across ethics committee members, researchers and clinicians’ data islands, there were several depictions of mechanisms which could grant individuals access to data based on pre-agreed permissions. This was further discussed in the debrief workshop, where participants described something like a ‘data passport’ for healthcare practitioners, which would allow access to patient data without repeatedly asking for clearance. At the heart of these conversations was a desire to have a way of making better use of and extracting more value from patient data.



A data island which includes a station that can issue ‘rapid access passes’ to a data library which contains anonymised data. *Researcher, Data Island*

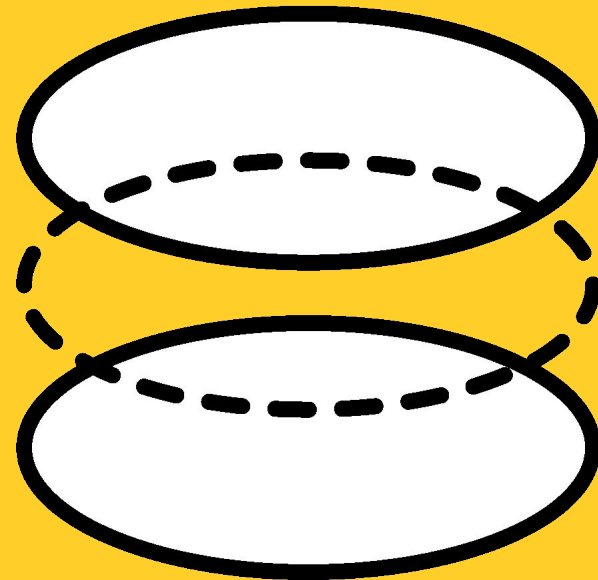
## Principle #2

## Be transparent about how data are used

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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.

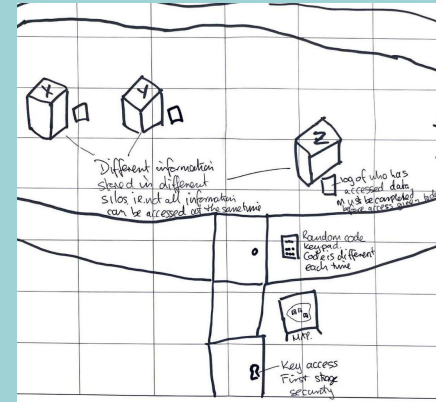
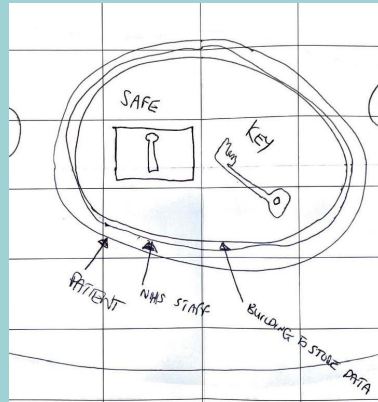
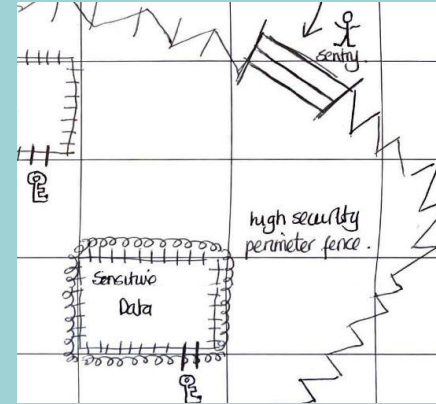


## Provocation

# Should patient data be stored in a fortress?

When exploring the various data islands, many used metaphors to describe locking patient data away in a 'safe place.' Some islands depicted high walls, razor wire fences, or complex vaults to represent this idea. However during debrief sessions (especially with survivors), we learned that many didn't actually have such strong preferences about how such data should be stored as long as it wasn't falling into the 'wrong hands'. This could imply that:

- they had multiple possibilities for data storage in mind,
- were uncertain about the specifics of the issue,
- felt ambivalent about data and its use,
- or simply were defaulting to tropes around data security in their drawings.



**Top Left:** A data island where data is stored in a castle's 'deep vault.' *Survivor, Extract from Data Island*

**Top Right:** A data island where 'sensitive data' is kept in a locked area within a 'high security perimeter fence.' *Trial manager, Extract from Data Island*

**Bottom Left:** A data island where data is stored in a safe. *Survivor, Extract from Data Island*

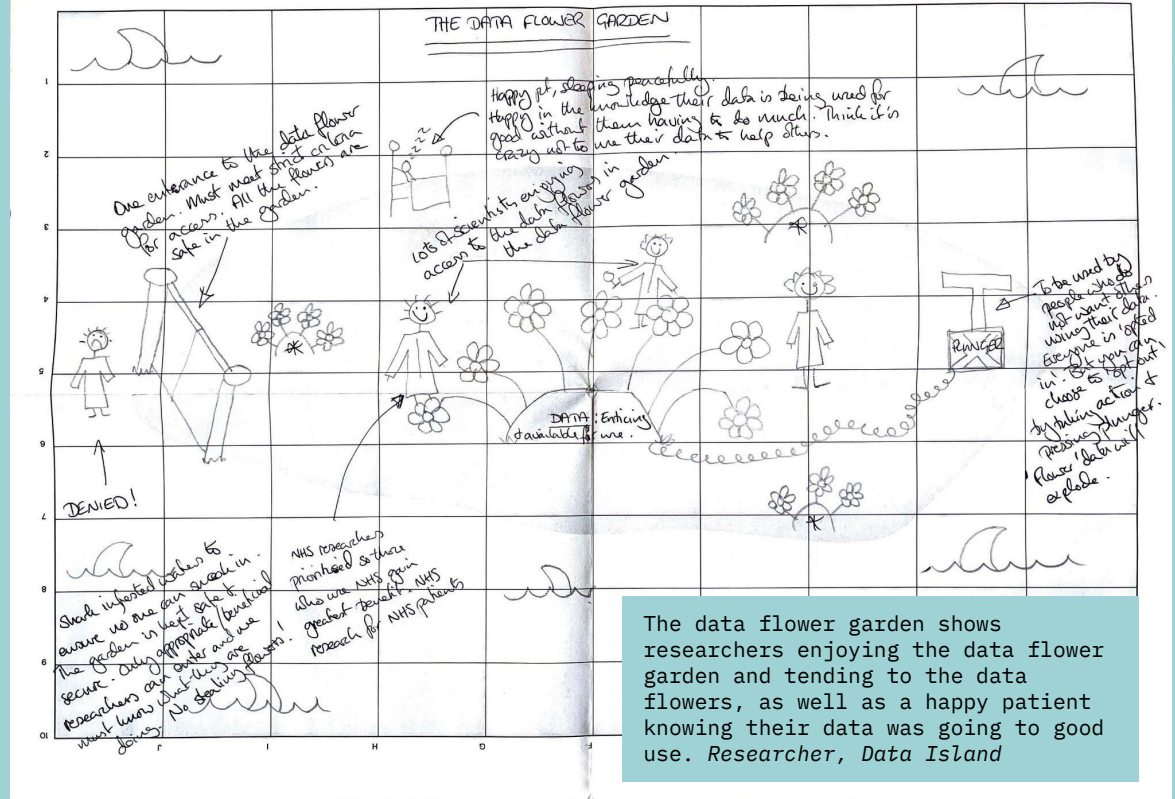
**Bottom Right:** A data island where data is kept in different silos and each person who wants access needs a key and a unique code to enter. *Clinician, Extract from Data Island*



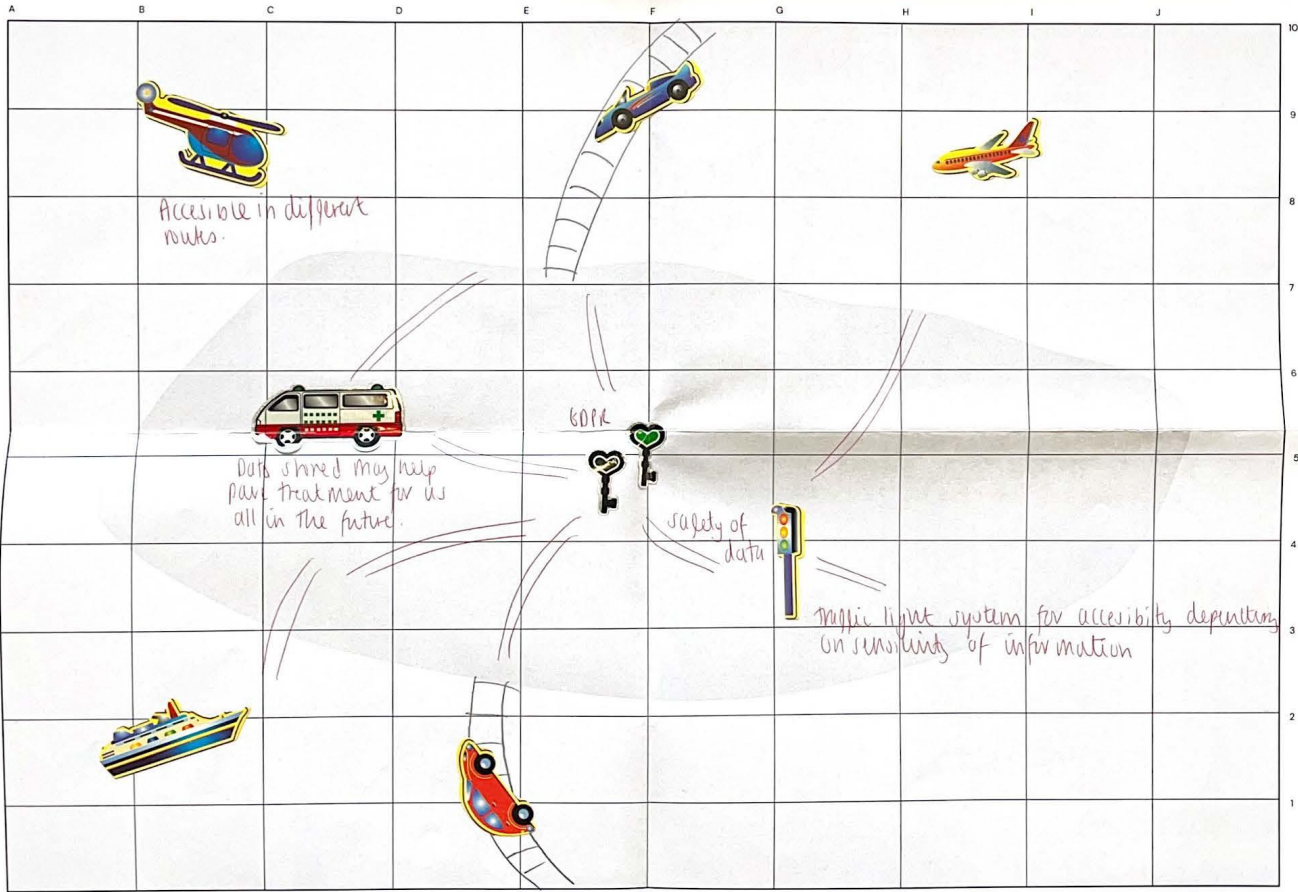
## Provocation

# Should patient data be planted and nurtured?

Another set of metaphors that emerged from the islands were ones that described lively, active places, aiming to nourish, respect and create value from the data they were collecting. For instance, this might be a 'data garden' where data is planted and nourished so it can create value, or a library that organises data in a way that makes it easy to work with and navigate. In these depictions, the public typically play much more of a role and the islands represent more collaborative environments. These islands aren't devoid of security, but place the emphasis on the use of patient data, as opposed to the means by which it is stored and protected.



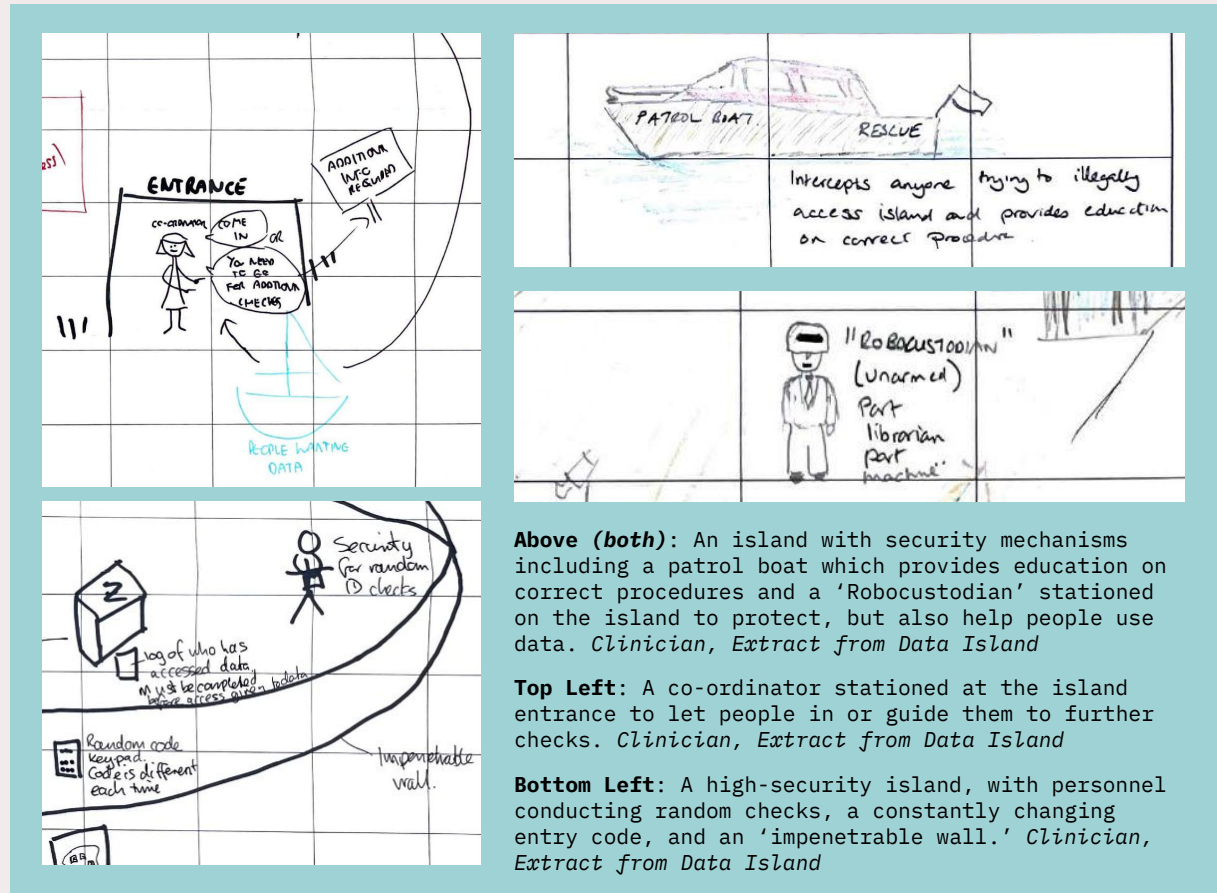
Draw and annotate your imaginary island here:



## Provocation

# What does the breadth of metaphors about security tell us?

The visions for a data island proposed various approaches to ensure the security of patient data. Some drawings depicted aforementioned intimidating security measures, such as high walls, razor or electric fences, or deep underground vaults. Other depictions, as we see here, showed more supportive and friendly forms of security aimed at aiding research, such as the 'Robocustodian' (an unarmed data custodian that is part librarian and part machine), or patrol boats that educate users on correct access procedures. These depictions reveal different value systems around data, and reflect the struggle to represent both the importance of data security and the goal of generating value from it in the same image.

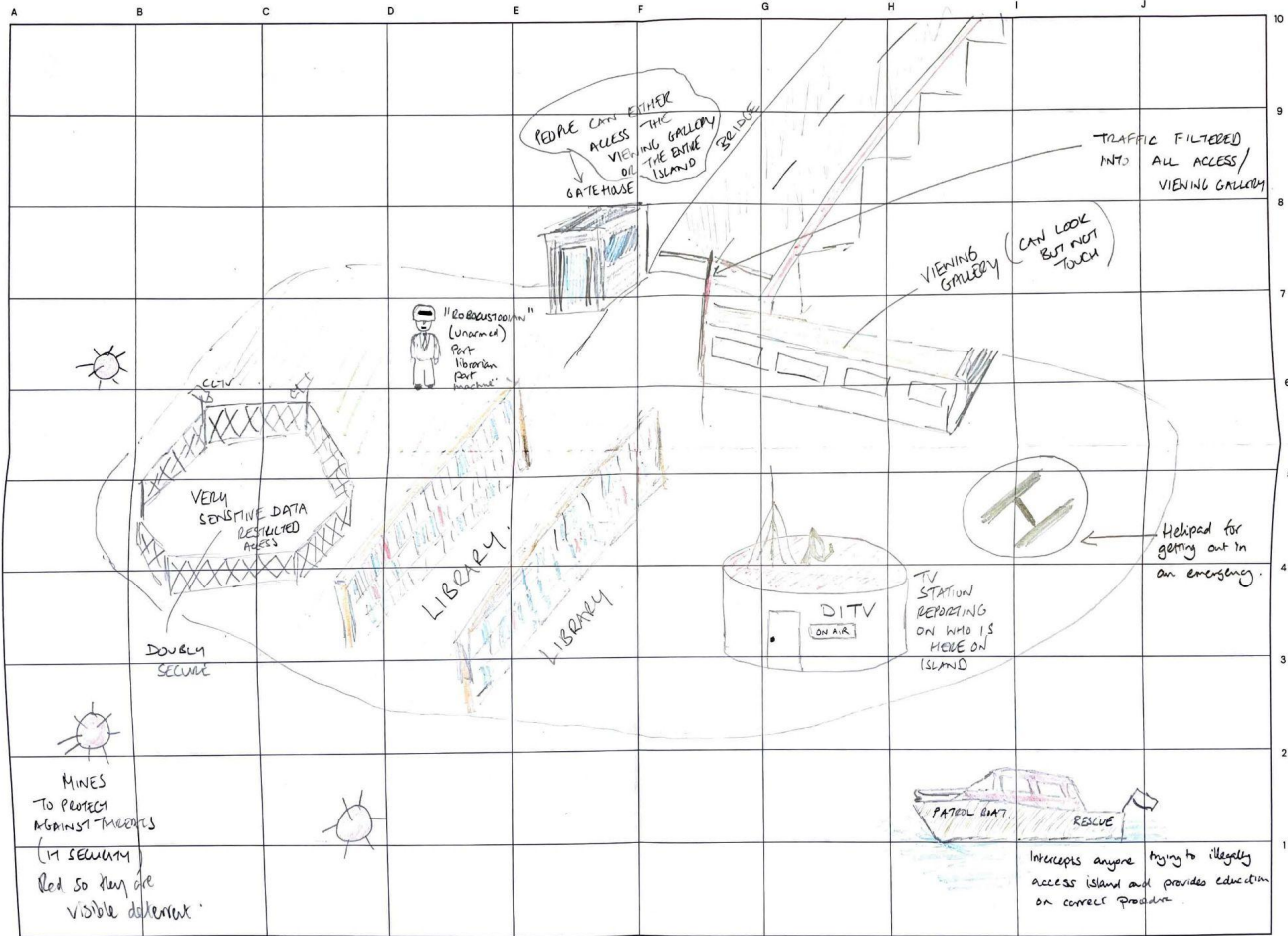


**Above (both):** An island with security mechanisms including a patrol boat which provides education on correct procedures and a 'Robocustodian' stationed on the island to protect, but also help people use data. *Clinician, Extract from Data Island*

**Top Left:** A co-ordinator stationed at the island entrance to let people in or guide them to further checks. *Clinician, Extract from Data Island*

**Bottom Left:** A high-security island, with personnel conducting random checks, a constantly changing entry code, and an 'impenetrable wall.' *Clinician, Extract from Data Island*

Draw and annotate your imaginary island here:

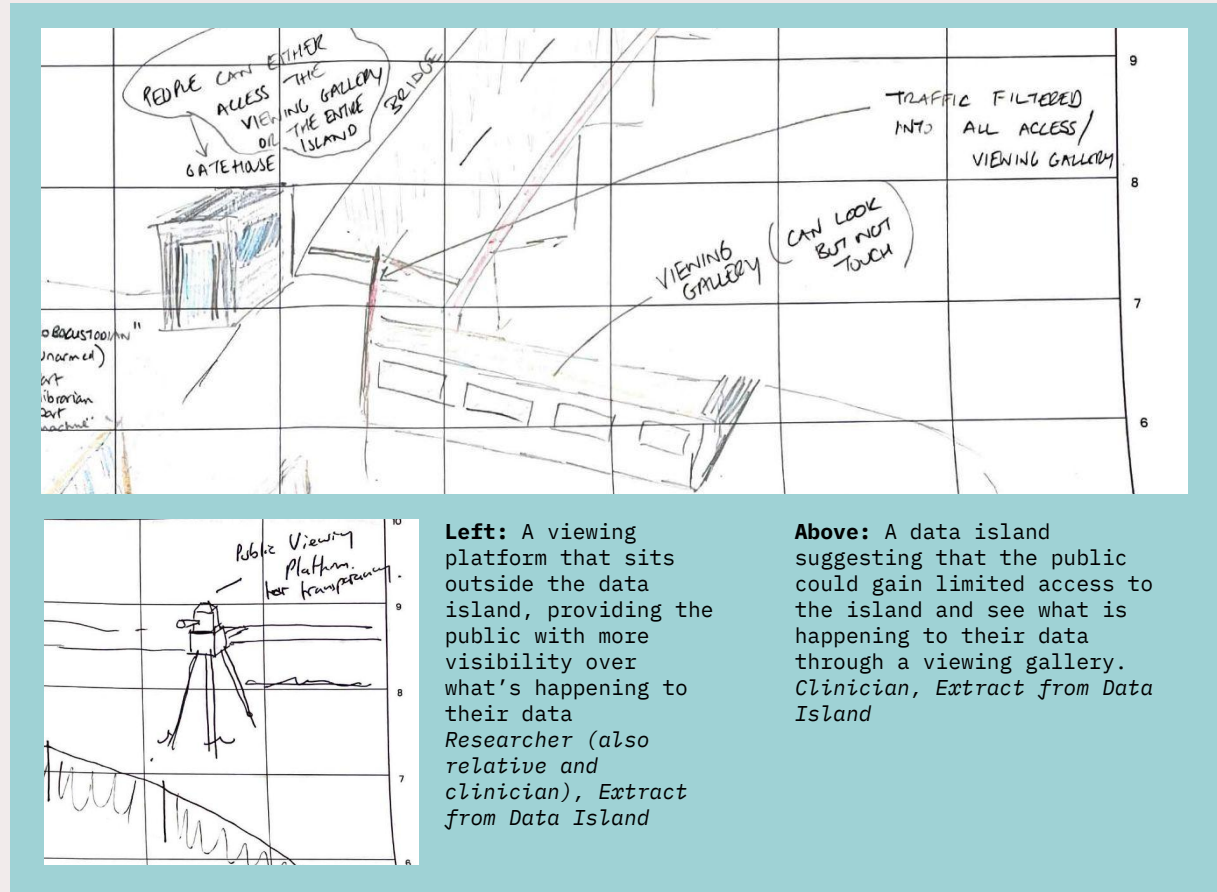


Clinician, Data Island

## Provocation

# What if patients could keep an eye on their data?

Across the probes, participants from all four groups proposed ways to help patients and their families better understand what was happening with their data. Some of the data island drawings included viewing platforms or galleries to represent the idea of making patient data more visible and understandable to the public. Other drawings suggested sharing anonymised patient data with the public. Throughout the debrief, participants suggested that in order for patients and their families to have more control and understanding over their data, greater transparency around data systems is necessary.



**Left:** A viewing platform that sits outside the data island, providing the public with more visibility over what's happening to their data  
*Researcher (also relative and clinician), Extract from Data Island*

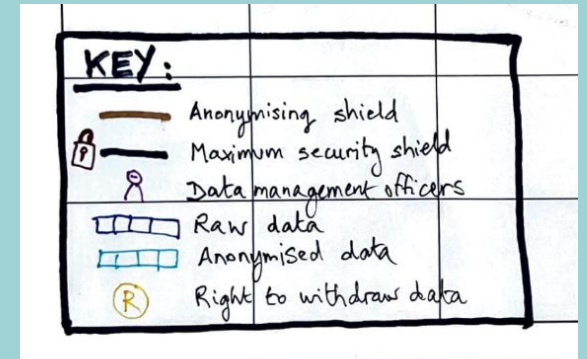
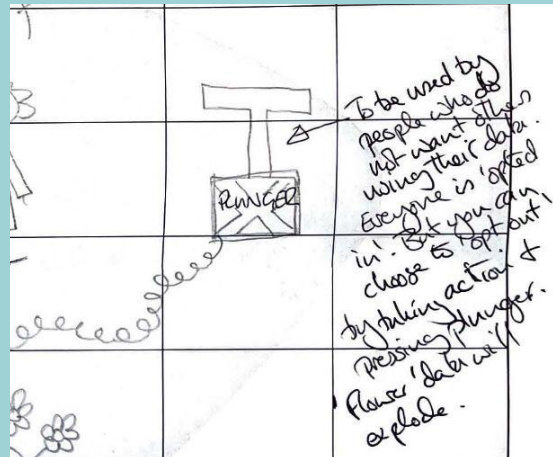
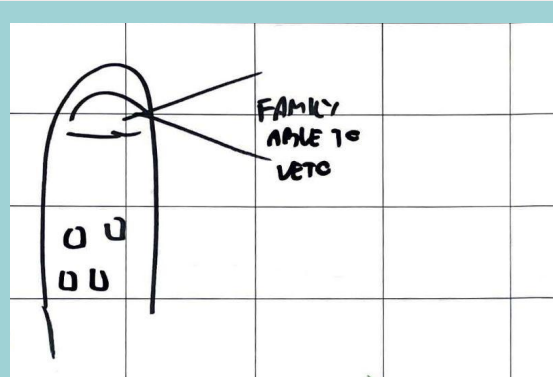
**Above:** A data island suggesting that the public could gain limited access to the island and see what is happening to their data through a viewing gallery.  
*Clinician, Extract from Data Island*



## Provocation

# What is transparency here? Is it about visibility, or is it about ease of influence?

Although most conversations about transparency emphasised the importance of visibility (being able to see what's happening with patient data), some suggested that a crucial part of transparency involves creating simple mechanisms for patients or their next of kin to withdraw consent. These themes were explored in data island drawings, where participants included elements that made it easier to revoke consent or control data — lighthouses that help family members veto certain activities, a detonator that could destroy data at any time, or just a simple way of communicating when and how consent can be withdrawn.



**Top Left:** A lighthouse on the edge of a data island giving next of kin the ability to see what's happening to data and 'veto' patient data usage.

*Clinician, Extract from Data Island*

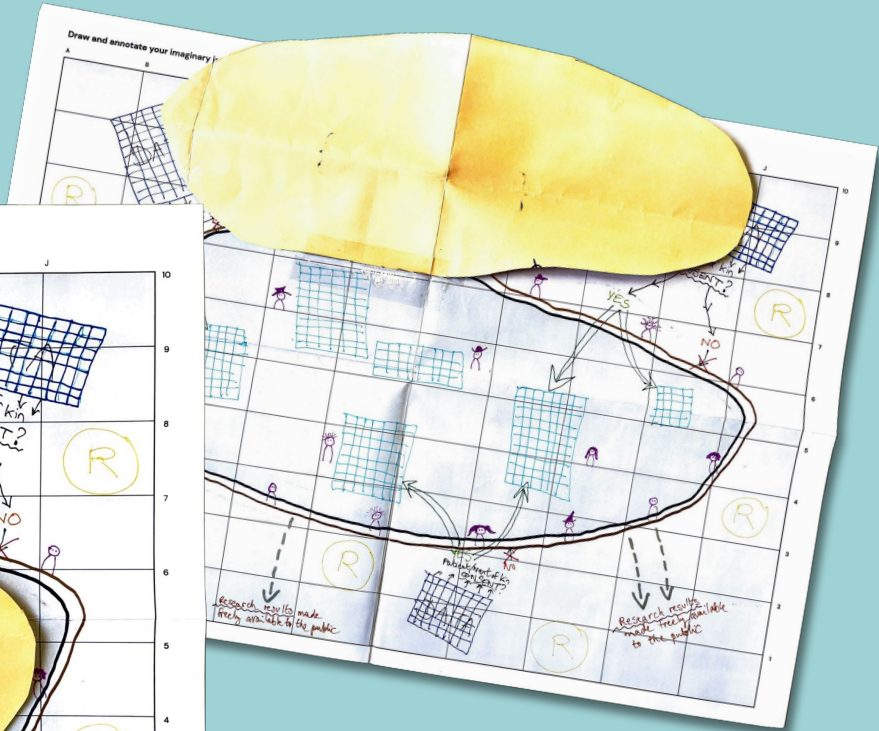
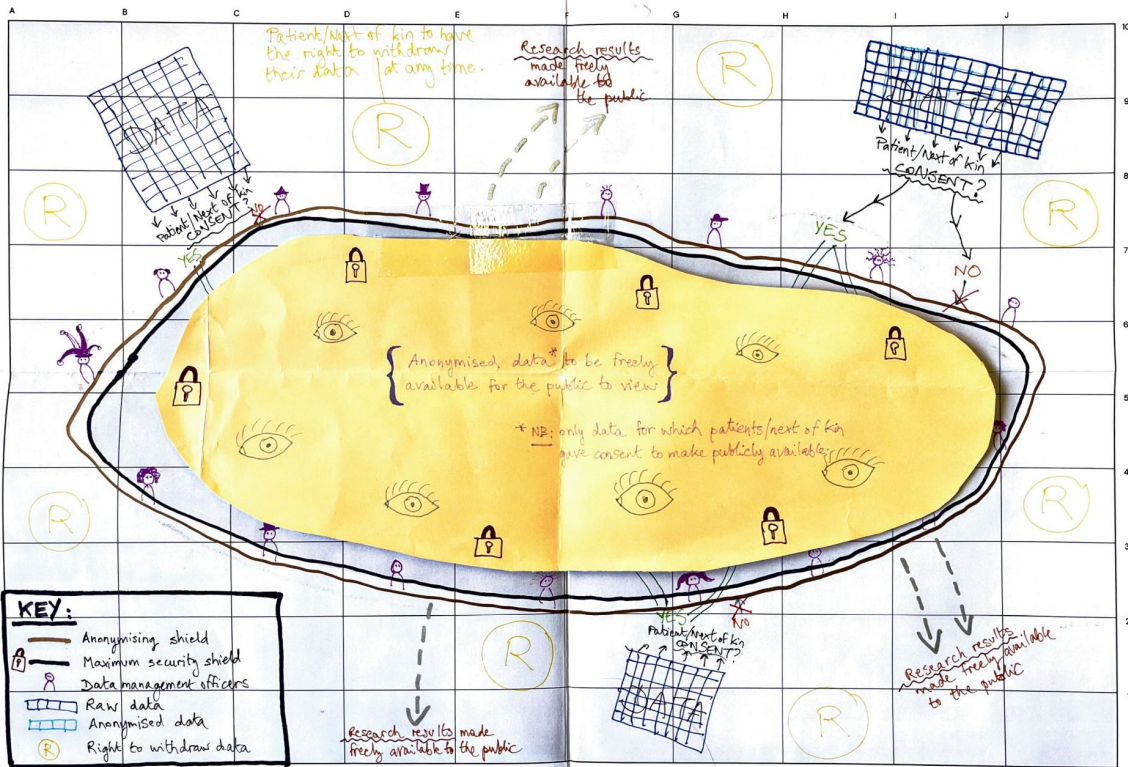
**Bottom Left:** A plunger that patients or next of kin can use at any time to 'opt out' and destroy their data.

*Researcher, Extract from Data Island*

**Top Right:** In the map key, R symbolises a right to withdraw data. This symbol is shown multiple times around the island, suggesting clear signposting of patients' rights to withdraw consent.

*Survivor, Extract from Data Island*

Draw and annotate your imaginary island here:



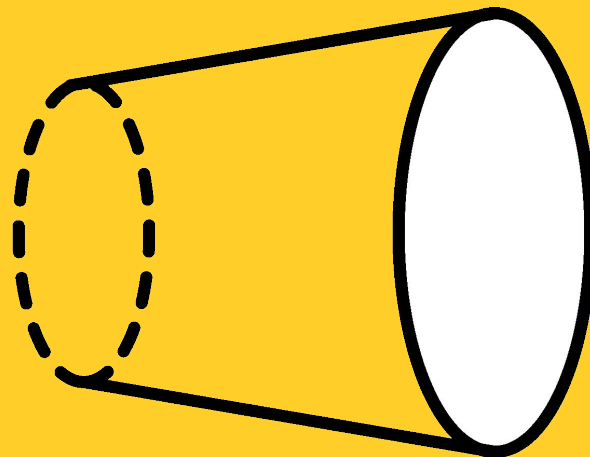
Survivor, Data Island

## Principle #3

## Form an identity around critical care research

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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.





## Provocation

## Does the public know what critical care research is?

Discussions during the debrief sessions exposed that many outside the healthcare system aren't fully aware of what critical care research is. For instance, some were unclear on whether entering into a research study would impact standard care. Others demonstrated this confusion through conversations about data, with survivors and family members struggling to conceptualise how patient data might be used within research. Clinicians and researchers echoed this, emphasising that some areas of research (e.g. cancer research or COVID-19 research) are very well known and play a prominent role in public discourse, but that this isn't the case for critical care research. Some described this low level of public awareness around critical care research as a significant barrier to effective consent and data collection.



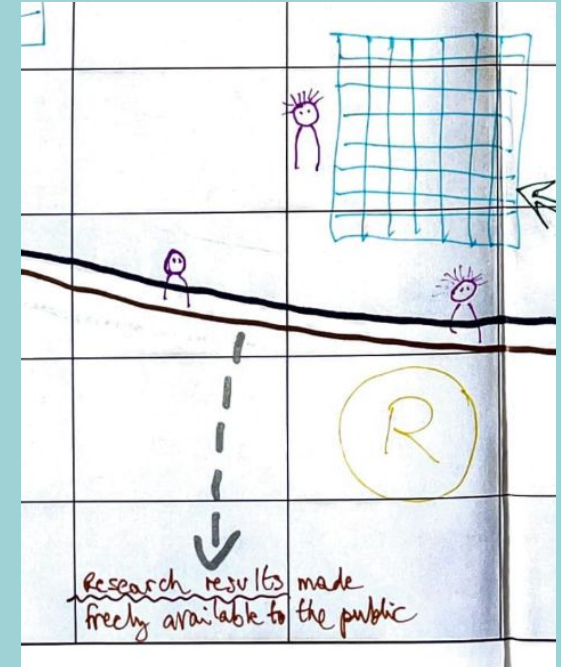
## Provocation

## How do we create engaged publics for critical care research?

One person suggested that for someone to provide informed consent in a critical care setting, the level of public awareness around critical care research needs to be so high that people are discussing consent 'around their kitchen table well before it becomes an issue.' Several of the visions of a data island suggested mechanisms to support this, raising public awareness through journalism, campaigns, or dissemination of research results. In conversations during the debrief, others started exploring what a PR campaign for critical care research might look like, arguing that elevating patients' stories would be an effective way to engage the public.



**Above:** A TV station reporting on critical care research activity that is using patient data.  
*Clinician, Extract from Data Island*



**Above:** A patient's data island which suggests research results should be made available to the public.  
*Survivor, Extract from Data Island*

## Provocation

## Is there a role for the public or survivors in influencing research?

Through our probe debriefs, survivors demonstrated an appetite to engage much more deeply with the topics being addressed in critical care research. They gave several examples of specific issues (usually experienced during or after their time in ICU) that they felt should be researched further and demonstrated an interest in influencing the research that happens in critical care. Such a response was unprompted, and raises questions about how participation and engagement in shaping research might impact the public profile and awareness of critical care research.

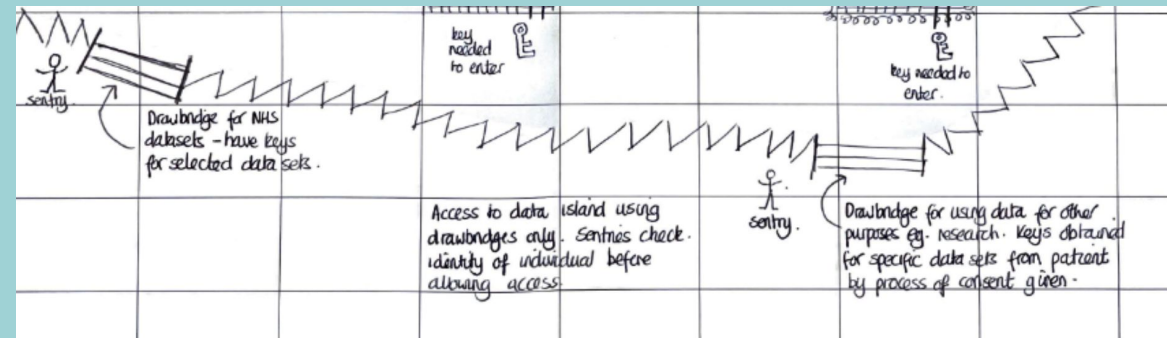




## Provocation

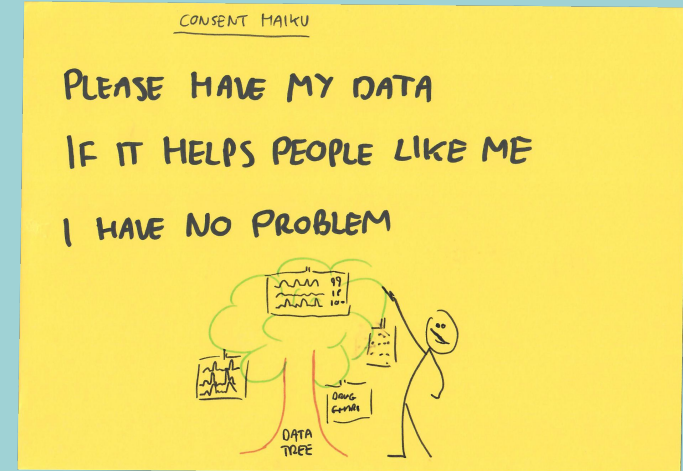
# What if sharing data was a way to support the NHS?

During debrief conversations and across cultural probes, the NHS was mentioned in several different contexts. Survivors were keen for data to be easier to access by the NHS than other parties; there were even some contentious suggestions by a couple of individuals that the NHS should profit from patient data by selling it on to private entities – although this was also explicitly mentioned by other survivors as a red line they would not like to see crossed. In all cases, survivors were keen to find ways to ‘pay it forward’ and support the institution, and the idea of being able to use data to do so was particularly energising for some.

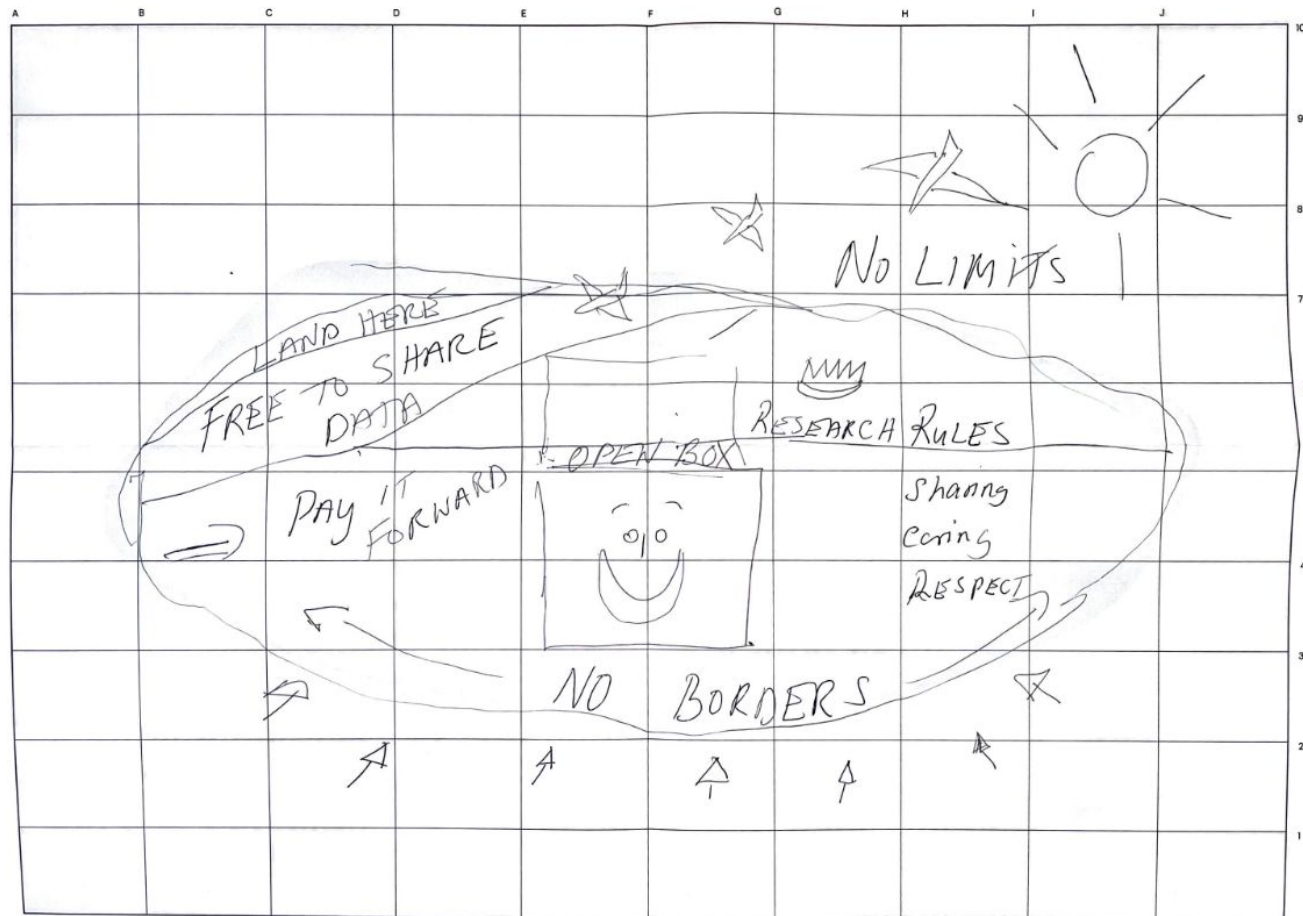


**Above:** A data island which has different means of access for NHS staff. *Researcher, Extract from Data Island*

**Right:** A haiku about consent written on a consent postcard. *Researcher, Consent Postcard*



Draw and annotate your imaginary island here:



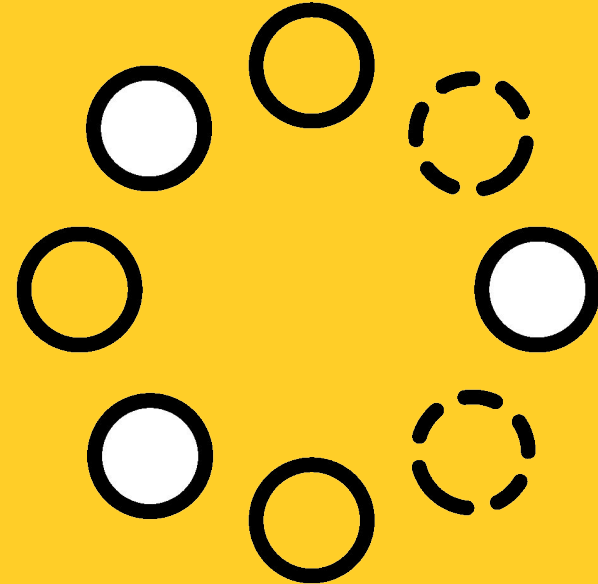
A data island built around a 'pay it forwards' ethos. Patient, Data Island

## Principle #4

## 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.



## Provocation

# How can a consent model make it easier for data to be shared and used?

In the voting activity, candidates who supported agendas that promoted sharing and using patient data received the most support. Nobody's first choice was to support an agenda that was opposed to sharing patient data, and most support was given to arguments that a) maximised the usability of shared data and b) proposed an opt-in by default consent system. This activity mirrored the sentiment across the group that it is important to share and generate value from patient data, and started conversations around the role that the consent model plays in framing the purpose and value of patient data.

## Huw Heiman – *The freedom party*

People may argue you should share your data, but it's not your responsibility. If you don't want to, you shouldn't have to. Vote for me to say NO to sharing data.

0%

## Fasi Fosse – *Pay-it-forward party*

Sharing your health data with our health service is the right thing to do. It might not directly benefit you, but it might help you in the future. That's why I back opt-in by default. Vote for me to join the 'pay-it-forward' movement.

34%

## Ben Borbington – *The access party*

I believe if we all contribute to research, we all benefit from research. Access to research data is for the greater good. Vote for me to give access to our data and create an accessible data bank, all for one and one for all.

46%

## Sally Sledgefield – *The choice party*

Many are losing sight of the real issue here. Medical research might be very sensitive, it is important for everyone to choose themselves whether they share data or not. Vote for me to protect our right to choose.

20%

Results based on participants' first and second choice votes

Candidates	Your vote
<input checked="" type="radio"/> <b>Huw Heiman</b> <i>The freedom party</i> People may argue you should share your data, but it's not your responsibility. If you don't want to, you shouldn't have to. Vote for me to say NO to sharing data.	
<input type="radio"/> <b>Fasi Fosse</b> <i>Pay-it-forward party</i> Sharing your health data with our health service is the right thing to do. It might not directly benefit you, but it might help you in the future. That's why I back opt-in by default. Vote for me to join the 'pay-it-forward' movement.	
<input type="radio"/> <b>Ben Borbington</b> <i>The access party</i> I believe if we all contribute to research, we all benefit from research. Access to research data is for the greater good. Vote for me to give access to our data and create an accessible data bank, all for one and one for all.	✓
<input type="radio"/> <b>Sally Sledgefield</b> <i>The choice party</i> Many are losing sight of the real issue here. Medical research might be very sensitive, it is important for everyone to choose themselves whether they share data or not. Vote for me to protect our right to choose.	
<input type="radio"/> Name: <i>New Exam Party</i> Point of view: <i>- Share data</i> <i>or pay your own</i> <i>Bill!</i>	

1

Candidates	Your vote
<input checked="" type="radio"/> <b>Huw Heiman</b> <i>The freedom party</i> People may argue you should share your data, but it's not your responsibility. If you don't want to, you shouldn't have to. Vote for me to say NO to sharing data.	
<input type="radio"/> <b>Fasi Fosse</b> <i>Pay-it-forward party</i> Sharing your health data with our health service is the right thing to do. It might not directly benefit you, but it might help you in the future. That's why I back opt-in by default. Vote for me to join the 'pay-it-forward' movement.	
<input type="radio"/> <b>Ben Borbington</b> <i>The access party</i> I believe if we all contribute to research, we all benefit from research. Access to research data is for the greater good. Vote for me to give access to our data and create an accessible data bank, all for one and one for all.	2
<input type="radio"/> <b>Sally Sledgefield</b> <i>The choice party</i> Many are losing sight of the real issue here. Medical research might be very sensitive, it is important for everyone to choose themselves whether they share data or not. Vote for me to protect our right to choose.	1
<input type="radio"/> Name:  Point of view:  	

2

Candidates	Your vote
<input checked="" type="radio"/> <b>Huw Heiman</b> <i>The freedom party</i> People may argue you should share your data, but it's not your responsibility. If you don't want to, you shouldn't have to. Vote for me to say NO to sharing data.	4
<input type="radio"/> <b>Fasi Fosse</b> <i>Pay-it-forward party</i> Sharing your health data with our health service is the right thing to do. It might not directly benefit you, but it might help you in the future. That's why I back opt-in by default. Vote for me to join the 'pay-it-forward' movement.	2
<input type="radio"/> <b>Ben Borbington</b> <i>The access party</i> I believe if we all contribute to research, we all benefit from research. Access to research data is for the greater good. Vote for me to give access to our data and create an accessible data bank, all for one and one for all.	3
<input type="radio"/> <b>Sally Sledgefield</b> <i>The choice party</i> Many are losing sight of the real issue here. Medical research might be very sensitive, it is important for everyone to choose themselves whether they share data or not. Vote for me to protect our right to choose.	1
<input type="radio"/> Name:  Point of view:  	

3

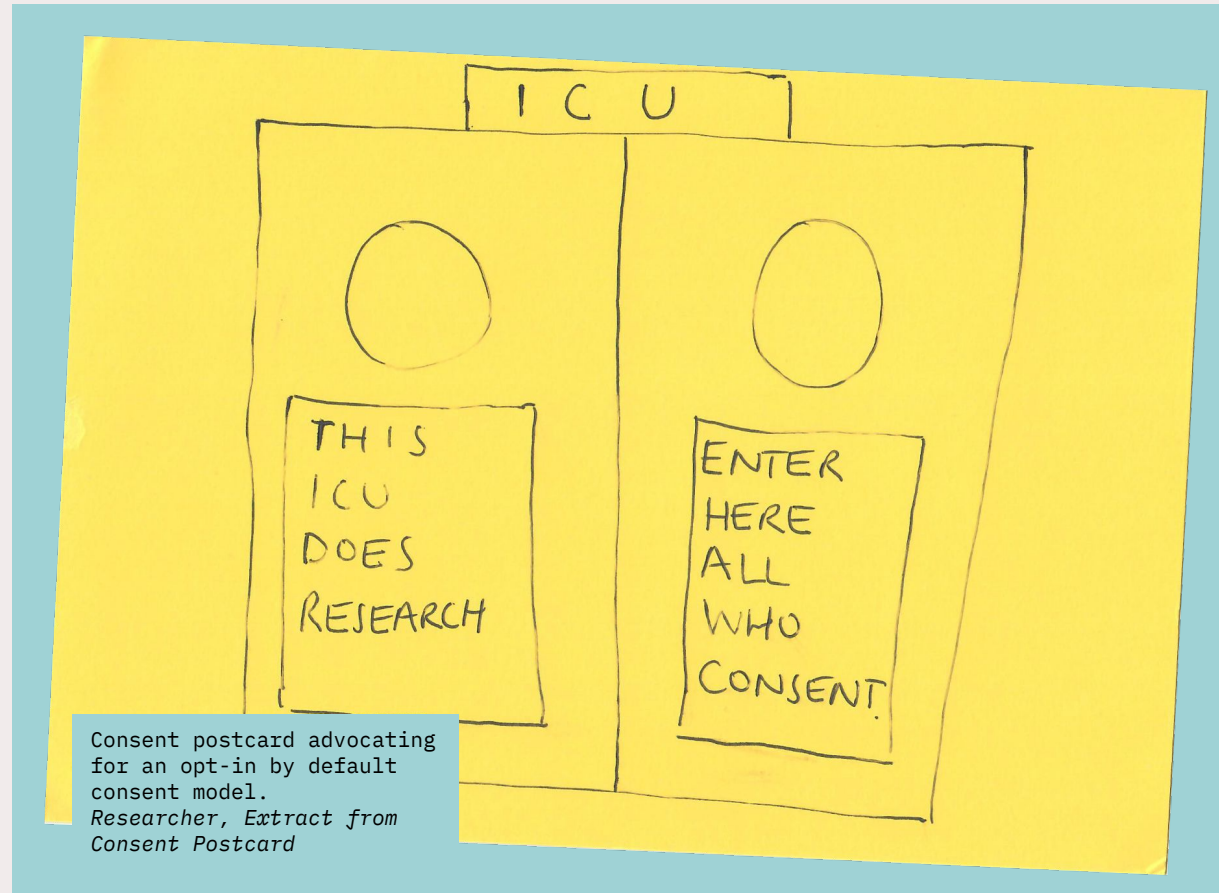
1. Researcher, Ballot Paper
2. Survivor, Ballot Paper
3. Clinician, Ballot Paper



## Provocation

## Is the research system robust enough to get rid of consent?

Within probes, and then expanded on through debrief conversations, there was an argument that research governance itself (the robustness of the research system – getting through the grant committee, getting research funded, and going through ethics processes) is far more robust than the clinical decisions made every day that clinicians typically aren't questioned on. Some say that having a conversation with patient/next of kin is enough of a consent process, others argue that there isn't even a need for a conversation and imagine an ICU that has an opt-in by default model.



## Provocation

## Could consent be obtained at a different time?

Several argued that the current model of obtaining consent for interventional studies forces a conversation at the wrong time. The model isn't sensitive to the unique challenges of conducting research in the ICU, for example failing to take into account the fluctuating capacities of patients. Some suggested that deferred consent is a good option, while others went further to propose that in an ideal world, consent would be collected before a patient even reaches the ICU, with comparisons made here to the model of opting-in to organ donation when registering for a driving license. Survivors enthusiastically conceptualised a sort of 'preferences passport' which could collect consent before entering the ICU, for instance through a conversation with a GP.



**Andthen.**

DEAR FUTURE ICU,

“No man is good enough to govern another man without the other's consent”  
Abraham Lincoln.

↳ ... but society would agree to consent to using data <sup>safely</sup> for the greater good.

DRAW A STAMP!



ICU

TH

TI

When asking for consent, patients and next of kin should feel trust that their data will be used to improve knowledge about their disease and how to improve care and outcomes for others. It's not appropriate to ask for consent when how personal data will be used is not explained to the individual or widely accepted in society to be acceptable.

It is not necessary to ask for next of kin consent when data are fully anonymised or where 'society' or legislation has agreed that data can be used without consent for NOK.

When you ask for consent, patients/family members should understand what data will be used for, how it will be protected, how anonymised it will be, and the potential value + benefits of using the data for future care/treatments etc.

Consent is informed in relation to the specific use or study.

Consent is not coercive or pressured. The process should be proportionately simple to minimise stress/anxiety, especially when time critical.

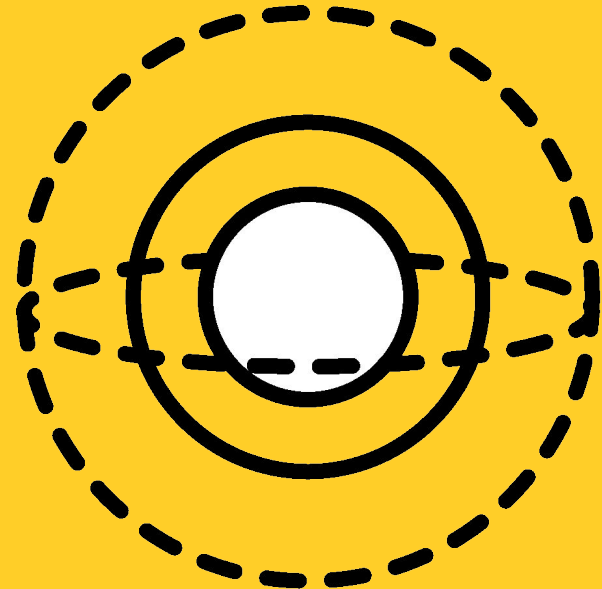
Clinician (also Researcher and Ethics committee member), Consent Postcard

## Principle #5

## Place the patient at the centre of the consent process

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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.'





## Provocation

## Does consent influence patients' sense of being in control?

While survivors didn't directly speak to wanting more 'patient-centered' approaches, at least not in those terms, this was raised often by healthcare professionals.

Several described consent as a 'gift,' and in conversation elaborated that interactions around consent should nurture the relationship between the patient and researcher, and should help both understand the significance of these interactions. Notably, some of the same participants who placed value on the act of giving consent also argued that consent may not be required, or that we should transition to an opt-in by default model. How might these two seemingly opposing visions come together?

"Consent is respectfulness."

*Survivor, Extract from Consent Postcard*

"Consent is a gift from a patient to the medical professional."

*Clinician, Extract from Consent Postcard*

"Consent is not taken, it is given."

*Ethics Committee Member, Extract from Consent Postcard*

## Provocation

## How do we make sure patients feel valued in such a challenging environment?

Clinicians expressed concerns about patients feeling dehumanised within critical care research, or only feeling that they were treated with care because of their potential value to research. Some felt that the current consent model doesn't support the right outcomes here, that the model isn't designed around the needs of a patient, and is instead designed around the needs of a governance process — it sacrifices patient wellbeing and understanding for the sake of a consent process that is administratively simpler. What might a consent model, that puts the patient's needs, feelings, and emotional journey at its heart, look like? And is this even realistic in an environment that must be so focused on patient outcomes?

“The doctors never explained to me how I was doing, and the only time anyone showed any interest in me was when they wanted me for research.”

*Clinician, Extract from 'one star' ICU guestbook entry.*

“People called me by a number, not my name. I was referred to as 'Bed 16'.”

*Clinician, Extract from 'one star' ICU guestbook entry.*



## Provocation

## Can an ill-fitting consent model cause harm?

Asking for consent in the midst of the chaos of a patient or next of kin's experience — the emotional pressure associated with a critical illness, and the small time window afforded to get a patient into research — is a well documented challenge. This was emphasised in the probes and discussions, with shared stories and depictions of the emotional context in which consent is requested. Building on the challenges of asking for consent in critical care, some explored the possibility that a consent model which isn't sensitive to this context, and which is unable to be responsive to a fast changing situation, could actually be an instrument that can cause harm.



I'M THIRSTY!  
WHY AM I TIED DOWN?  
ARE MY BOOTS ~~BELOW~~ THE BED?  
WHY ARE YOU TRYING TO KILL ME?



DON'T ASK ME FOR CONSENT - I WON'T GIVE IT IN THIS STATE!

AND I'M NOT SURE I CAN TRUST ANYBODY ELSE TO GIVE CONSENT ON  
MY BEHALF (IN MY CONFUSED STATE)

IT'S NOT APPROPRIATE TO ASK <sup>THE PATIENT</sup> FOR CONSENT WHEN THE PATIENT IS DELIRIOUS  
OR IS NOT COGNITIVELY CAPABLE

IT'S NOT NECESSARY TO ASK ANYBODY FOR CONSENT IN A LIFE-CRITICAL SITUATION  
- MEDICAL REQUIREMENTS HAVE PRECEDENCE, AND THEY SHOULD BE ALLOWED TO GIVE  
CONSENT FOR RESEARCH - THIS SHOULD ONLY BE THE CASE UNTIL THE MEDICAL  
CONDITION HAS STABILISED. IF NO NEXT OF KIN CONTACTABLE, MEDICAL STAFF CAN GIVE CONSENT  
AS LONG AS CONSENT IS SOUGHT (PATIENT/NEXT OF KIN) AT EARLIEST OPPORTUNITY

## Provocation

## How might a more responsive consent model help people feel genuinely 'informed'?

When discussing their probes, some participants suggested that the consent process is often satisfied with patients or next of kin being 'theoretically informed' as opposed to genuinely informed. They explored ideas around a model more suited to the unique context of the ICU, one that can adapt to the situation, varying the level of consent attained, or the amount of information shared based on the complexity or time-criticality of the situation. Some conversations moved beyond this altogether, exploring how patients and next of kin might be taken on a journey of understanding, noting that a consent model may support this in some way.

"It is not appropriate to ask for consent when the consultee is distracted, and feels compelled to agree to research."

*Researcher, Extract from Consent Postcard*

"The process should be proportionately simple to minimise stress and anxiety, especially when time critical."

*Ethics committee member, Extract from Consent Postcard*

"The consent process is nonsense. It is rarely informed – relatives are distressed and confused, or just want to sign the form to 'help' in whatever way possible."

*Researcher, Extract from Consent Postcard*

## Provocation

## Is requesting consent patient-centred?

Some reflected on the trade-off between the 'burden of consent' and the sensitivity or risks of the research, concluding that in some situations there is no need to ask for consent at all, for instance when what's being consented to is low risk — as is already the case with the use of pseudonymised routine data. Others suggest that consent shouldn't play a role in life-threatening emergencies — that there isn't room for a conversation about consent in such emotionally charged, time-critical situations. Perhaps thinking that we need a patient-centered consent model is a blinkered way of looking at the challenge, and what we really need is to consider whether consent as a mechanism is patient-centered in the first place?

"It is not necessary to ask for next of kin consent when data are fully anonymised."

*Ethics committee member, Extract from Consent Postcard*

"It is not necessary to ask for next of kin consent when you are not giving any specific treatment, just using data like observations etc."

*Clinician, Extract from Consent Postcard*

"Consent is not necessary."

*Survivor, Extract from Consent Postcard*

## Provocation

## What is patient-centered consent?

In the consent postcard activity we asked people to explore what an ideal consent model might look like in the future, yet many struggled to move beyond existing tropes of consent. All participants did, however, outline a consent model that was more centered around the patient's needs, which:

- Clearly explains risks and benefits
- Fosters an environment that encourages questions
- Influences the way patients or next of kin feel
- Makes it easy to say 'no'
- Is sensitive to language
- Gives time to make a decision

Responses here beg the question, how do we move beyond current regulatory framings of consent and reimagine a radically different model?



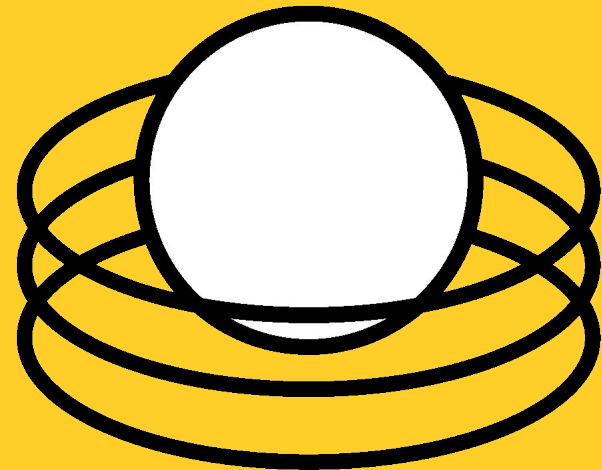
Survivor, Consent Postcard

## Principle #6

## Create a research environment which cares for the patient

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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.



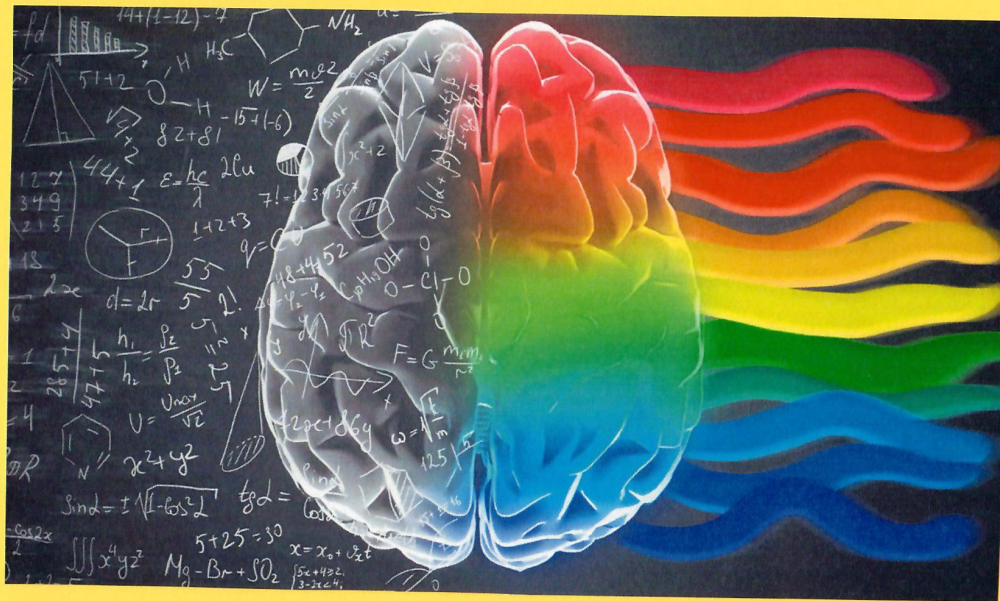


## Provocation

## How can research nurture a journey of understanding?

The disorientation, confusion and sudden change in context for patients and next of kin as they arrive in critical care was detailed by participants, who pointed out the importance of good communication in mitigating a sense of fear and confusion. Communication here was seen as part of care, and the potential for research to help to ground a patient and support them and their next of kin in understanding what's happening was noted. Some also discussed how a journey of understanding extends well beyond the end point of research, and how communication (as a form of care) should also do so. They suggested that closing the loop with research participants, sharing findings and research outcomes could also be seen as an important element of care.

FROM QUESTIONS + CONFUSION . . . .



Researcher, Consent Postcard

. . . . TO UNDERSTANDING + PEACE



## ICU Guestbook

Your review:

**I FELT REALLY CARED FOR...**



When an ICU nurse brought me a fan to my bed I felt the cool air on me and the wizzing sound comforted me. My husband brought me one into the ward. Later, Apart of course from the medical care, the touch of a hand  
Toucheit

Your rating of the ICU out of 5



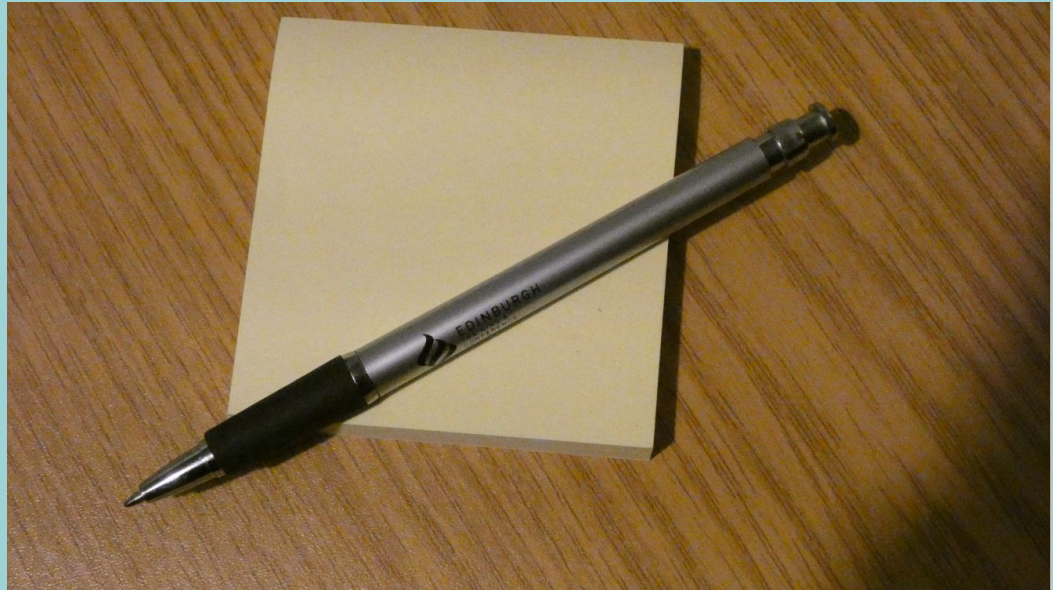
On mine gave me great comfort. Seeing my daughters was a great comfort and my son. messages from friends and relatives. I felt I mattered to the nursing staff. I was happy to talk to the researchers. They made me feel human again, giving my opinions,  
MY OWN OPINIONS

Survivor, '5 Star' ICU Guestbook entry.

## Provocation

## What small gestures might help a patient feel a sense of agency?

Through the ICU Guestbook activity, participants talked at length about the experience of moving into a space where suddenly patients lose all control of what is happening to them. They described positive experiences as those where patients feel a sense of involvement in decisions, and therefore a sense of control, yet also acknowledged the tension between this and the pragmatism required in the ICU. Research, and particularly questions around preferences and consent, were noted as opportunities and moments for patients to feel some sense of control; a decision about consent may be the only thing they can control. What small mechanisms and moments within critical care research, like handing a patient a pen, might help them feel some sense of agency?



The patient who submitted this photo shared the story behind the image. When they were in ICU, a research nurse came to speak to them about a study, and gave them a pen. In that moment, they described the simple gesture of being given a pen as one that made them feel 'seen as a human with opinions.'

*Survivor, Photography submission*



## Provocation

## How can we help next of kin support and care for patients?

ICU guestbook responses suggested that positive experiences of research care were envisaged as 'holistic' in terms of human relations. Survivors described the importance and impact of their friends, particularly through photography activities, where they placed value on connections with loved ones by photographing familiar people, or objects signifying personal connection. Family and friends were imagined as a part of a holistic, supportive ICU research environment. Others noted the importance of supporting family, friends and/or next of kin in addition to the patient. In thinking about care in this holistic way, one might ask how caring for next of kin in the context of research is also a way of caring for the patient?



"Staff were brilliant at looking after my loved ones - staff know how crucial that is too. The 'holistic' approach is excellent and key."  
*Patient , Extract '5 star' from ICU Guestbook*

**Left:** *Ethics committee member, Photography submission*

## Provocation

## In the ICU, does a mundane home comfort have special significance?

When asked what they would take with them into critical care, participants shared photographs of mundane, homely objects (toothbrushes, teabags, glasses), or even just photos of their home – things that would help them feel a sense of familiarity and home comfort. Many also shared photographs relating to technology such as laptops, wifi icons, charging cables, headphones and radios. Such responses hint at a desire for familiarity and some way to ease into an alien, high functioning environment full of medical devices and unfamiliar technology. Not to be interpreted too literally, these images don't necessarily suggest that teabags or headphones are the answer, but rather highlight the significance of small, mundane pleasures in a place where they are so rare.



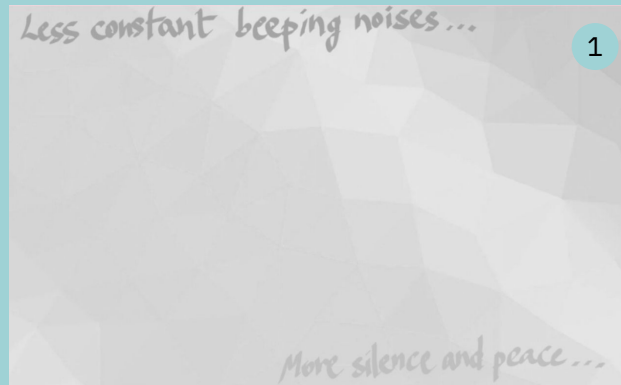
Andthen.

## Provocation

## How does a research environment provide sensory forms of care?

While critical care research deals in absolutes, hard truths, and quantitative data, patients' experiences are affective, sensory and constantly in flux as their physical capacities change over time. Submissions through the photography activity shared the importance placed on the senses, and survivors recounted how intense and distorted their experiences were when slipping in and out of delirium.

The ICU is a very particular form of sensory space, and several noted the importance of considering sensory experiences as part of care. How can a world of research which deals in data and speaks a different language contribute to the sensory, tactile dimensions of a caring environment?





## DEAR FUTURE ICU,

I DIED IN THE AMBULANCE ON THE WAY HERE, WAS RESUSCITATED BUT NEEDED MANY OPERATIONS TO SAVE MY LIFE AND MY LEG. I WAS OBVIOUSLY INCAPABLE OF GIVING CONSENT, WHICH MY WIFE DID ON MY BEHALF. I WAS DELIRIOUS, CONFUSED AND HAD NO IDEA WHERE I WAS, OR WHY. ICU SEEMED A VERY IMPERSONAL PLACE - I ACTUALLY BELIEVED YOU WERE TRYING TO KILL ME! IN THAT STATE, I COULDN'T BE REASONED WITH - MY COGNITIVE ABILITY WAS THAT OF A 2-YEAR-OLD. THE ONLY THING THAT MIGHT HAVE MADE ME MORE SECURE (AND THEREFORE LIKELY TO GIVE CONSENT) WOULD HAVE BEEN TO HAVE BEEN TOUCHED, OR TALKED TO - I WAS THE NIGHTMARE PATIENT WHO WOULD PULL OUT ALL THE TUBES (I THOUGHT THEY WERE A SCI-FI MEANS OF IMPRISONING ME) IN ORDER TO GET SOMEBODY TO BRING ME A CUP OF TEA!

DRAW A STAMP!



ICU

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THE FUTURE

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THE YEAR 2032

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**What's next**

# What's next / Our hopes for the future

## Conversations

There is a live debate around consent in ICU research to which this project has added additional voices.

We are looking forward to seeing what happens when we introduce the mugs and pens into ICUs and other places. What will the quality of those conversations be like, and will they make people look at these questions in a fresh light?

We must continue to involve a range of stakeholders in these discussions, and develop new conversations out in the world.

## Questions

How can this project help change consent in ICU research whilst maintaining patient and public trust and safety?

How can we create communication pathways so that there is a better understanding between stakeholders around what constitutes “patient data”, and the risks and benefits of its use for research?

How do we address the needs, concerns and desires of different stakeholders?

What can we learn from this work about how to create a research environment that cares?

## Methods

Building on the insights gained in this work, we now want to think about how to involve wider publics in these discussions. Possible methods include citizens’ juries and other forms of deliberative engagement.

Design and arts-based methods help to create a space for different voices in debates around consent in healthcare. They also change the texture of those debates and encourage people to think outside the box. Going forwards, we hope to develop these methods in innovative ways to help address a range of healthcare-related questions.

# Thanks!

 ICU Heart

 Critical Care Futures Journal

We would like to acknowledge:

#### **The core project 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), and Freyja Harris (Andthen).

#### **The cultural probe co-designers**

Jean Antonelli (University of Edinburgh), Dr Monika Beatty (NHS Lothian), Joanne Mair (University of Edinburgh), and Goutam Das (PPI Representative).

#### **All of the participants**

We would like to give special thanks to all those involved in this project, without whom it would not have been possible!

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