

**i**n Theatre

**K** **N** **O** **W** **L** **E** **D** **G** **e**  
**i** **s**  
**P** **O** **W** **E** **R**

Research + Art  
**Collaborative Zine**

**2022**

# Our Project

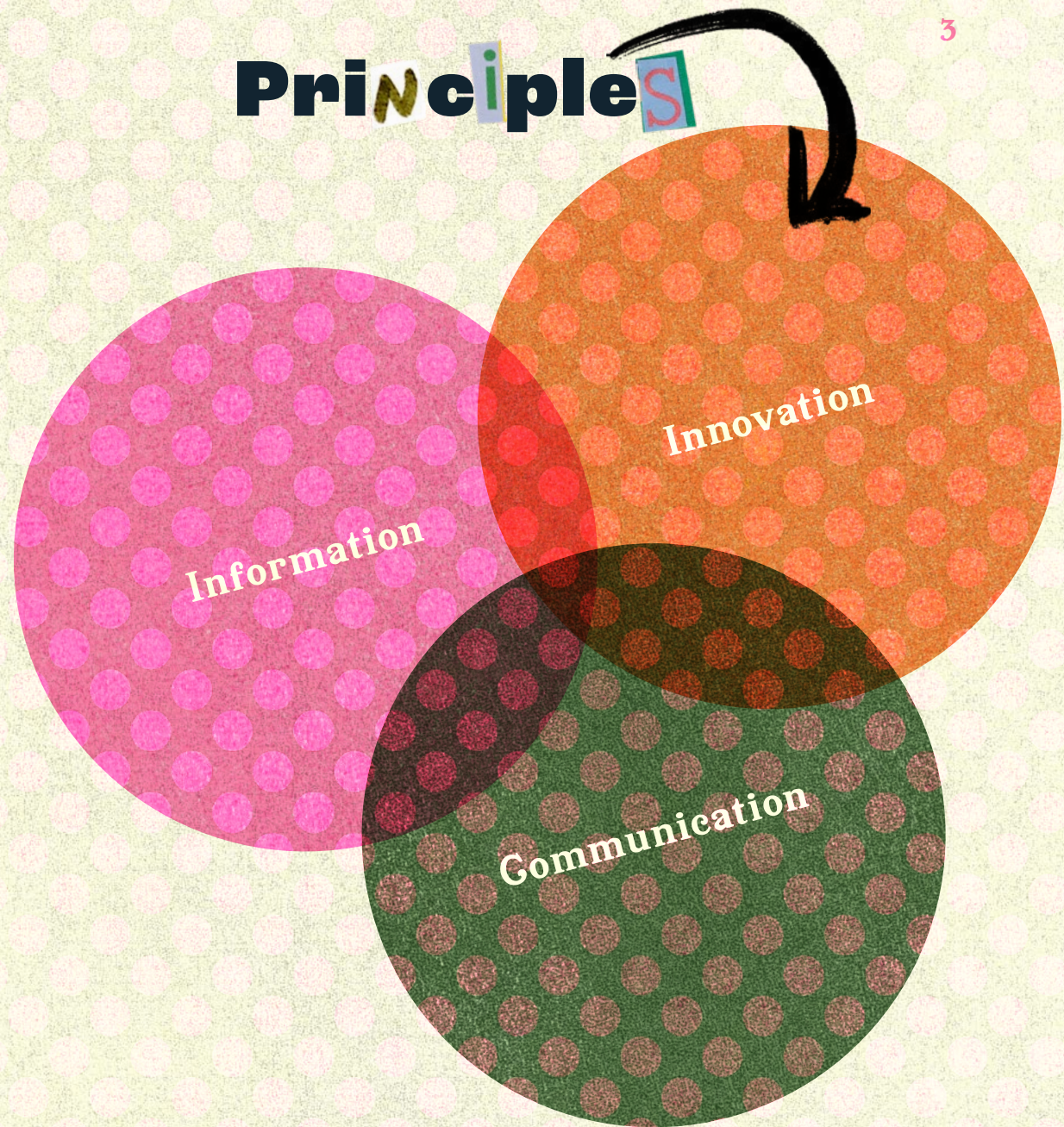
**T**hrough a collaboration with a **healthcare engineer** who specialises in materials science research and a **designer** we ran an interactive zine making workshop which facilitated conversation about what people may want to know before undergoing surgery.

Based on these discussions and the zines made by participants we established three **key principles**:

- > **Information**
- > **Communication**
- > **Innovation**

## Principles

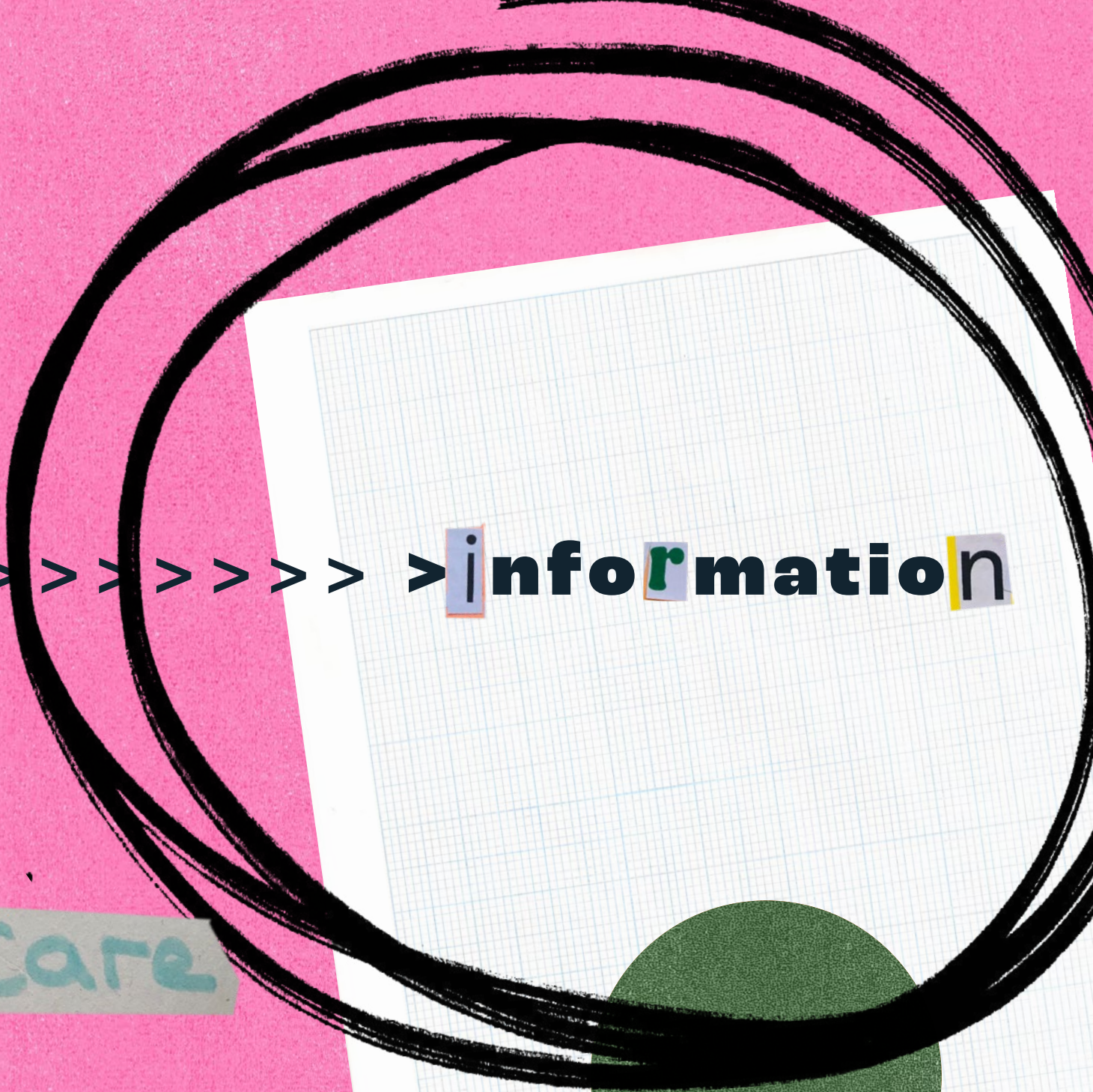
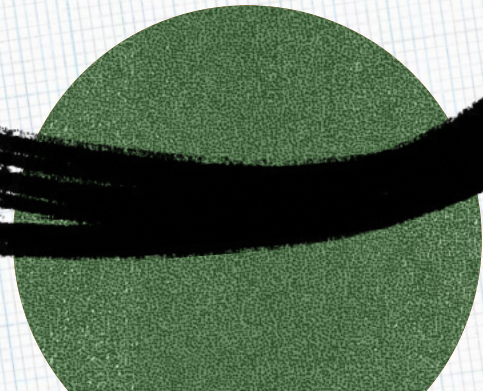
3





> > > > > > > > > > > > **information**

Safe



# Information is key

The discussion brought to light a lot of ideas around **information, who has information and how much.**

Information needs to be meaningful.

Information about after-care and how to live with potential complications is important.

Information needs signposting

Participants reflected on how **important accessibility and signposting of accurate** information was to them.

Despite the fact there may be many NHS patient leaflets online and patient groups which are valuable resources: patients **need to know how to access** them.

How and what Information shared needs to be patient-specific



**Information**  
 =  
**Knowledge**  
 =  
**Power**

**O**ver the course of the workshop and reflecting on the session as a team, it was clear that **information about the diagnosis, procedure(s) and potential complications, helped people build their knowledge** which **empowered them to make decisions**

> **Knowledge empowers patients and helps them do more accurate research**

> **Knowledge is comforting, helping patients to feel more prepared and relieving anxiety**

**Knowledge**  
 + **Time**  
 = **Fundamental**

**K**nowledge and information are important, but we **should also factor in time**. Some participants felt it was challenging for the brain to process information at the point of diagnosis.

**It is even more challenging to be expected to make life-changing decisions at this point.** This process could take time: hours, days, weeks. Therefore time to process once initial knowledge and information has been shared **should go hand in hand.**

But what happens during this time, once a patient has walked

out of the room? There may not be a chance to ask important follow-up questions once the patient has started processing information, **making it hard to gain more knowledge.**

This **can result in a circle of anxiety** and unhelpful googling. Which brings us back to themes of sign posting to information once the patient has had time to process knowledge as this could be extremely helpful.





# Our Communication Needs



Time

Availability

Consistency

Relevance

Empathy

In our workshop, we found that some patients felt that when healthcare workers took more time when communicating with them, it improved their confidence and provided comfort during an emotionally intense time. Clear communication was found to help to reassure patients about what will happen, or has happened.

## Time

By taking time when communicating, healthcare workers **can improve patient confidence** and provide comfort during an emotionally intense time. Clear communication from clinicians helps to reassure patients about what will happen, or has happened. It was noted that hurried communication can decrease confidence in Clinicians and increase anxiety.

## Consistency

Patients found that a **consistent clinical message, communicated compassionately** was key to the care they received.

---

## Relevance

**Clear communication with relevant information** can help patients feel more prepared and less anxious prior to and during procedures. This worked best when clinician **didn't assume** prior knowledge when communicating. As well as **being sensitive** to what and how much information the patient wants to know and knows already. For example, this could be creating a patient-specific frame-of-reference (or as close to universally accessible frame of reference) as possible when describing things like medical device size, incision size, tumour size etc. as the 'size of a grain of rice', or the size of an 'apple seed'

---

## Empathy

During our discussion many noted how much an **empathetic approach can impact on patient confidence and anxiety**. Communication needs include sensitive and respectful communication and by keeping patients up-to-date with your medical information.

---

## Availability

When a practitioner **takes time to answer your questions during diagnosis and pre and post-procedure** it can make a big difference. The availability of specialist staff e.g. specialist cancer nurses, to discuss medical details which can directly impact on comfort and anxiety.





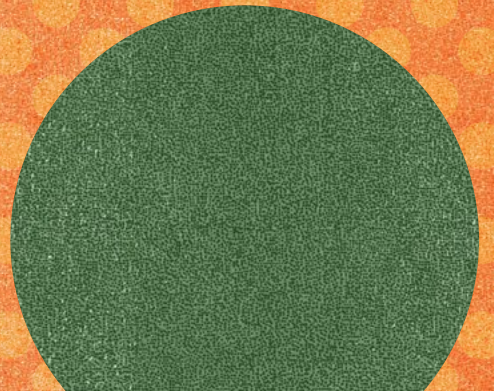
## Top Tips for Patients

- ◆ **Don't be afraid to ask questions** and challenge the Clinician when you don't understand something or need clarification.
- ◆ Don't be afraid to **say you don't understand** technical jargon/scientific terms.
- ◆ **Ask where you can find further information**, for example, if there are any pamphlets, on websites with useful information, through medical societies with patient-facing resources, as well as through relevant charities.
- ◆ Ask if there are any **relevant patient groups** you can access and where to find them.
- ◆ Ask about **potential complications** and what they may mean.
- ◆ Ask about **after-care** and living with potential complications i.e. what is a normal post-operative experience?
- ◆ Ask **who can you talk to** about further follow-up questions.
- ◆ If it is feasible, write down questions that you have **in advance** of your consultation.
- ◆ Write down any questions that you have **after the consultation**, as they crop up.
- ◆ Ask the Clinician to **identify someone that you can talk to for support**, further information and advice - there should be a cancer or specialist nurse (or even a charity helpline) - all of which are available to help you as your first point of care and taking your care forward.

Innovative



> > > > > > > > > > > > i n n o v a t i o n



## Innovation

# What did we learn when discussing innovation.



**We also took time to reflect on the innovation of the work and technology and how this might impact patient experience.**

In general, workshop participants viewed clinical ultrasound most positively, whether it was used as an external imaging technique, or an internal imaging technique.

We spoke about new materials around scientific innovations and how participants felt about them.

Interestingly, the everyday material 'glass' was **considered fragile** in the context of clinical use and something that will go inside someone's body.

Overall, when discussing innovative materials for medical devices, participants were **reassured by their use if the benefit outweighed the risk.**

The fact that **we can learn from the past** and the way previous scientific advances are **embraced are both comforting.**



### Viewpoint

**Considering innovation through the patient's eyes can be useful.** For example, even though keyhole surgery is beneficial as it might result in a much smaller scar, for the patient, this is still a scar and might be significant.

### Excitement

**There was excitement and enthusiasm** around new scientific medical advances and how they could help patients and improve healthcare.

This **encouraged more animated conversation** than the technical details of the advancements themselves.

This is important to consider when sharing innovation in **patient-facing communication and education**

### Positive Steps

Many workshop participants agreed that the development of **multimodality technologies is a positive step** if it minimises number of interventions.

### Progression

The more each device can do, the fewer procedures patients need which **participants felt was a bonus** of the innovation and technological progressions.



## Innovation

### Ownership

'Ownership' came up as a key concern – whether it **was ownership over your own body during** medical and clinical processes. Something to consider with innovation is ownership over such things as medical images.

For example, if researchers do a small proof-of-concept trial, could they give patients the images that they took of the patients, even if the images were not diagnostic.

### Risk vs Benefit

We also spoke about the risk and benefits that come with the use of new technologies e.g. nano materials and how **it felt important to discuss what is the risk vs. benefit with a clinician.**

### Sharing

Our discussion and research highlighted **the importance of developing an infrastructure** (like websites, animations, films, podcasts and other media) to help support the knowledge building and communication stages. This should be done adjacent to developing new technologies to help improve access and public perceptions.

## Questions

Some questions that arose in our discussion around innovation. These might be good prompts to reflect on.

As a patient, what else might you want to know, or do any of these questions resonate with you?

**How much would you like to learn about new technologies?**

**How much would you like to know about how new technologies work?**

**What are your thoughts/feelings on the use of new technologies? As well as technologies that use nanomaterials?**

**What are your thoughts/ feelings on the use of new technologies that use glass fibres?**

**Do you have any worries about new medical technologies?**

**Which do you find more comforting, that you are being treated with cutting edge technology, or that your treatments have been tried and tested a long time?**

**Find more information about our research  
at: [www.interventionaldevices.org](http://www.interventionaldevices.org)**

## Acknowledgements

Thank you to all the patients who participated in the zine workshop and discussed their experiences with us.

Thank you to Sacha Noimark for introducing us to her research. You can read about what Sacha and her colleagues do here:

**[www.interventionaldevices.org](http://www.interventionaldevices.org)**

Thank you to Soofiya for facilitating the workshop and designing this zine based on what we discussed

**You can find out about our projects here:**

[www.ucl.ac.uk/interventional-surgical-sciences/public-engagement/public-engagement-projects](http://www.ucl.ac.uk/interventional-surgical-sciences/public-engagement/public-engagement-projects)

**You can find opportunities to contribute to  
medical research on People In Research:**

[www.peopleinresearch.org](http://www.peopleinresearch.org)

**For local cancer services, please contact Tower  
Hamlets Borough Council:**

[www.towerhamlets.gov.uk/ignl/health\\_\\_social\\_care/public\\_health/cancer.aspx](http://www.towerhamlets.gov.uk/ignl/health__social_care/public_health/cancer.aspx)

This project was made possible by a research enrichment grant (UNS113144) from Wellcome ([wellcome.org](http://wellcome.org)) and by the Engineering and Physical Sciences Research Council (EPSRC) and UK Research and Innovation (UKRI) through their EPSRC UKRI Innovation Fellowship (EP/S001506/1)

## In Theatre

This research zine summarises the findings of the workshop with people who have experienced surgery.

You can find out more about the research and project at:

[www.ucl.ac.uk/interventional-surgical-sciences](http://www.ucl.ac.uk/interventional-surgical-sciences)

Designed by soofiya.com



wellcome  
EPSRC centre  
interventional+  
surgical sciences