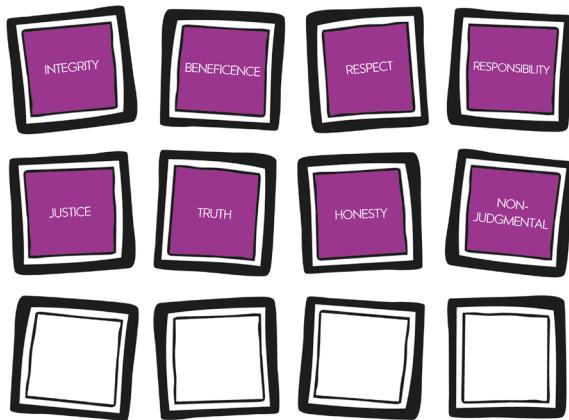


VALUES

Values underpin everything you do. But do you share the same understanding of key values with your team members. What do you think are the most important values for working within the context of your project?

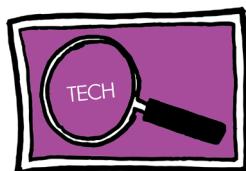
You'll find 8 value cards in the pack, which can be used in different ways to create conversations within your team. Add additional values that you think are important to the blank cards in the pack.



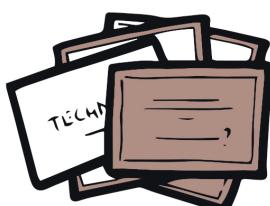
PROMPTS & ACTIVITIES

You may need to explore these values through a different lens to define them in terms of specific contexts and disciplines. Explore the values under the different lenses provided that are relevant to you... or create your own!

Eg. Technology,
Health, Design,
Psychology



To encourage further thought or discussion, use the value cards with the provocation cards. For example, if you want to open the conversation around technology further, grab the technology provocation cards...



PROMPTS

- / How do you define these values?
- / Are there values that you personally or professionally hold that are not included here? If so which ones are missing? [Add them to the blank cards]
- / Are there any values listed that are in conflict with personal or professional values? What will you do with this knowledge?
- / How do these values relate to the research questions that you are asking?
- / How might these values be reflected in how you develop your research, design and methods?

CAPTURE

As you are facilitating the activities, it's important that another team member is in charge of capturing the discussions and decisions.

For the values activity we have enclosed 2 worksheets to help in capturing an overview that can be referred to throughout your project:

- / **Our value definitions**
- / **Using a lens**

We suggest that you revisit and adjust your captured notes at every key team meeting to remind and realign the team. You can also re-run the activities to establish changes as a project progresses.

RESPECT

RESPONSIBILITY

NON-
JUDGMENTAL

INTEGRITY



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AND CUT]

JUSTICE

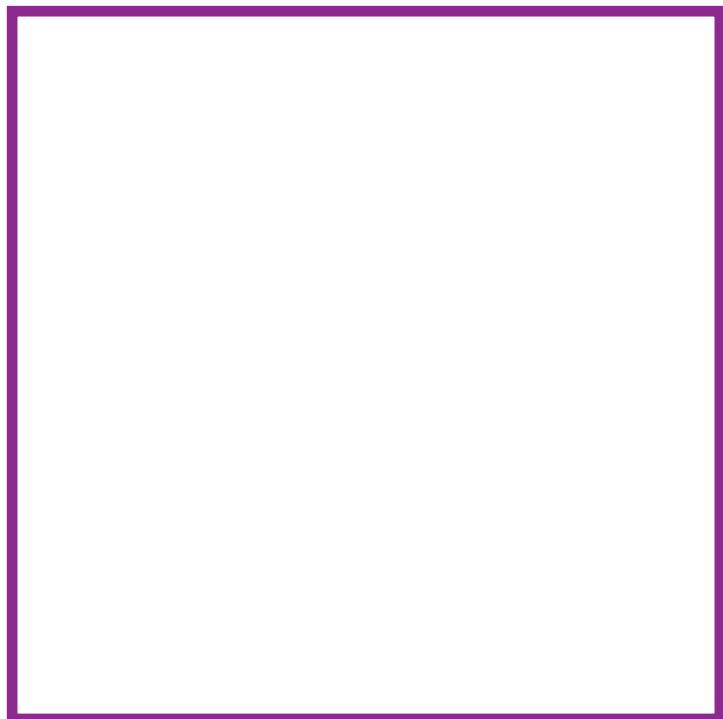
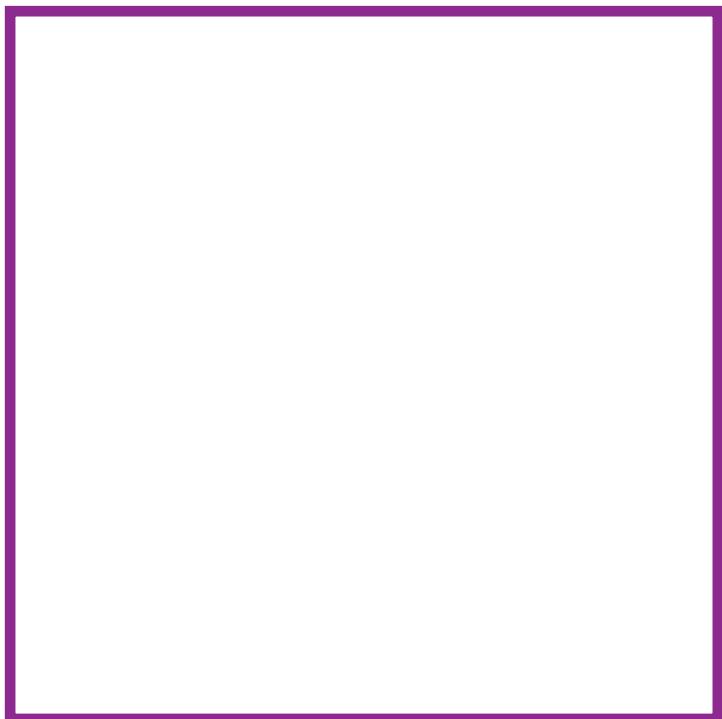
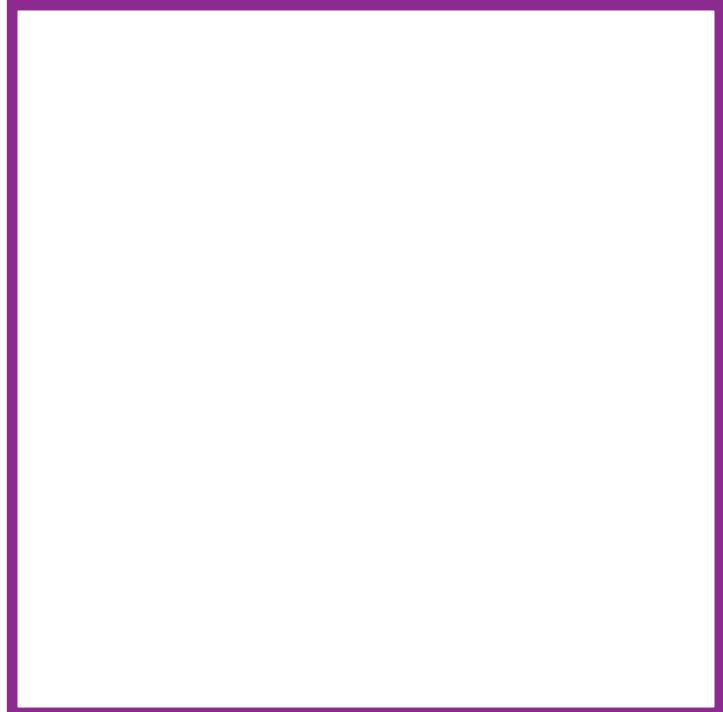
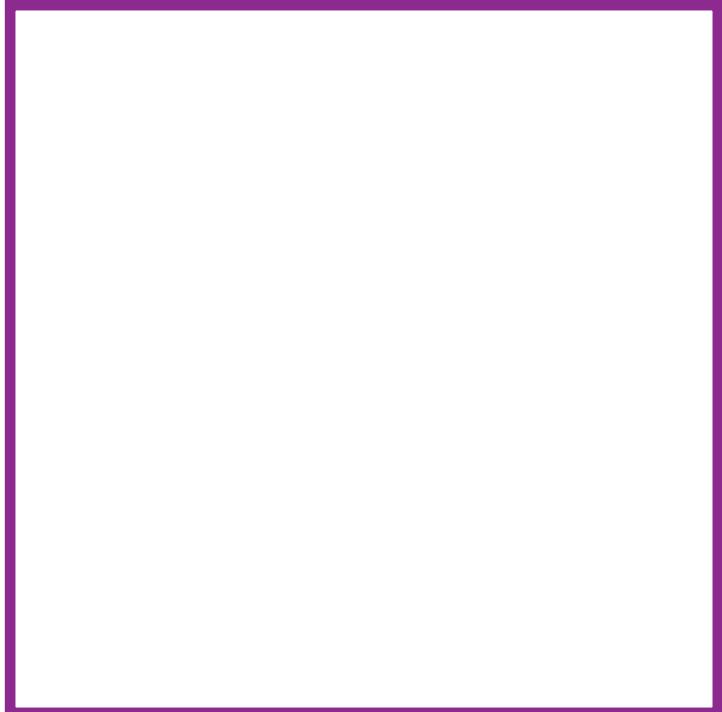
HONESTY

TRUST

BENEFICENCE



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AND CUT]



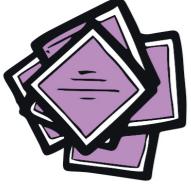
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AND CUT]

VALUE CARDS

What do you value the most?

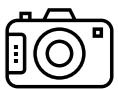
Which values most relate to the research questions that you are asking?

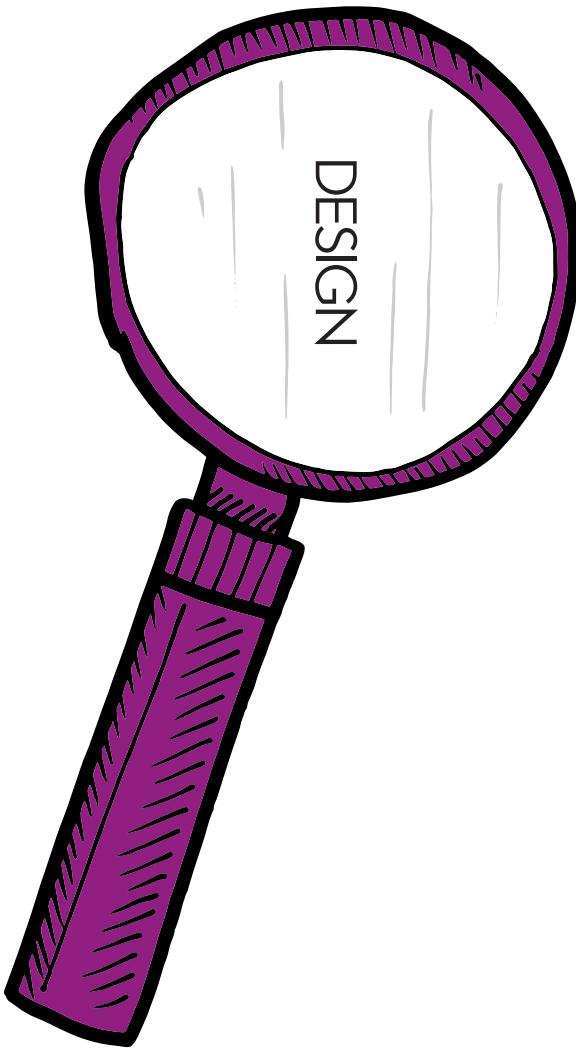
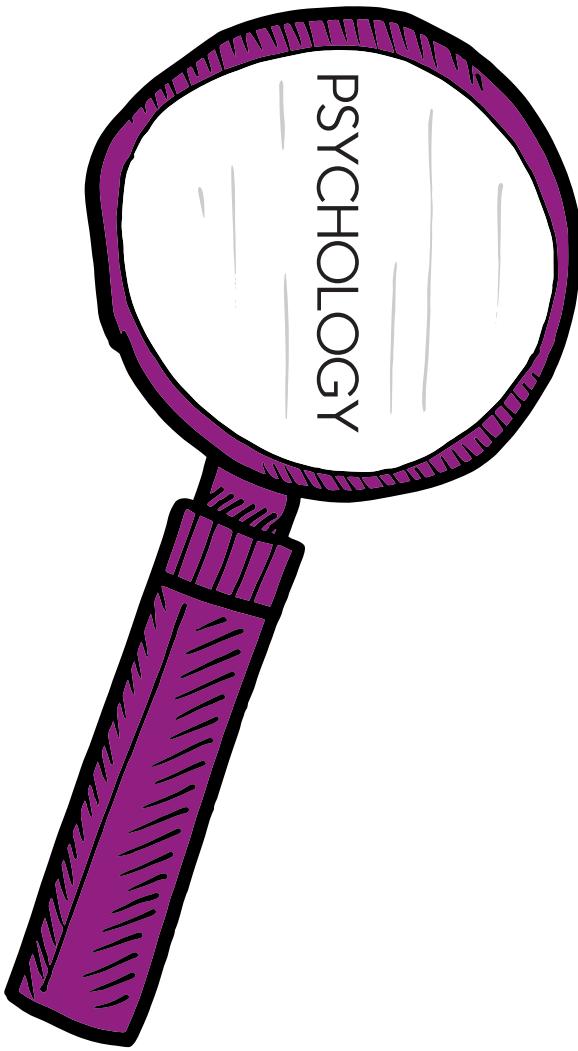
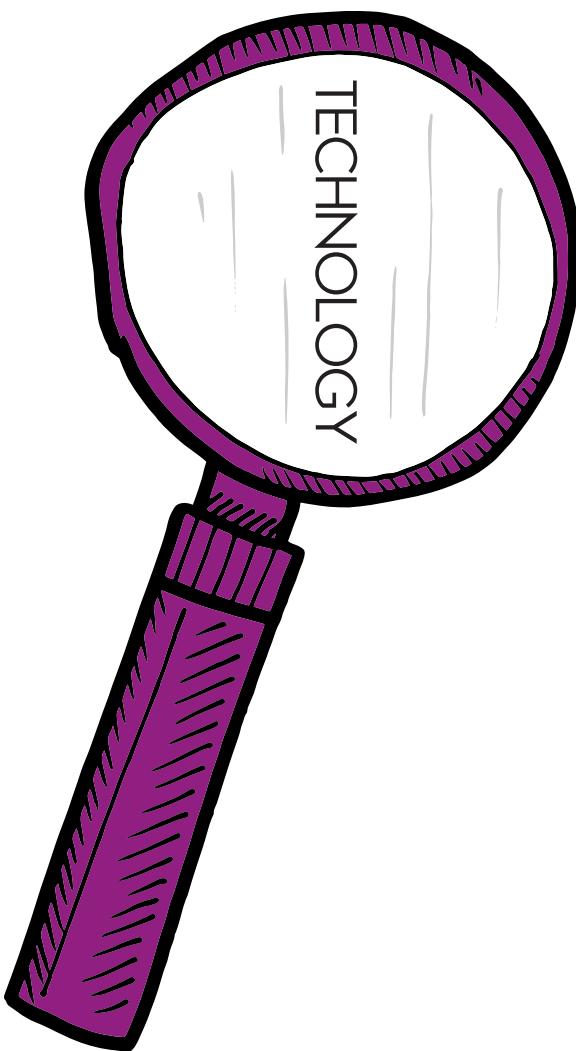
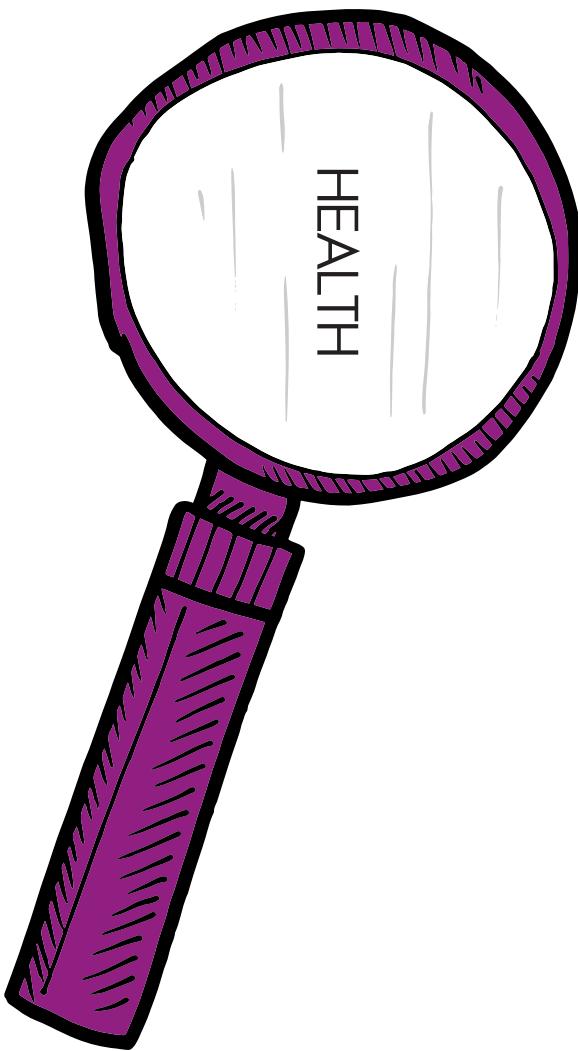
Which values do you closely relate to?



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Add this to a digital document by photographing





OUR VALUE DEFINITIONS

CAPTURE

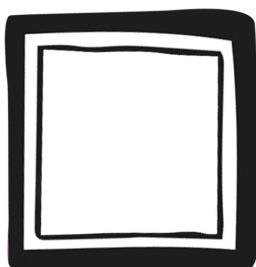
Capture your team's definition of the values below.











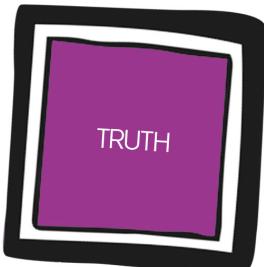
OUR VALUE DEFINITIONS

CAPTURE

Capture your team's definition of the values below.



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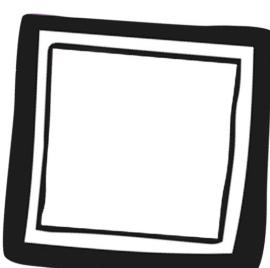
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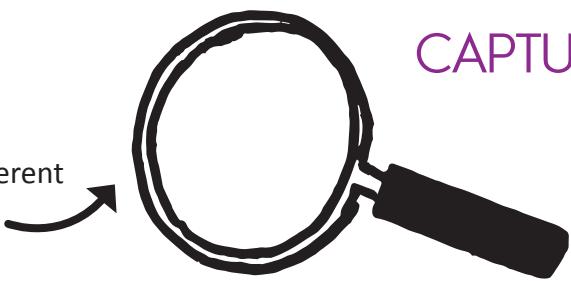


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USING A LENS

CAPTURE

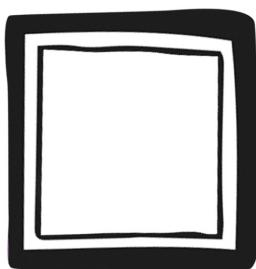
Capture your team's definition of the values below under a different lens. Note the lens you've used in the magnifying glass...









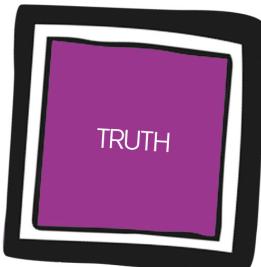


USING A LENS

CAPTURE

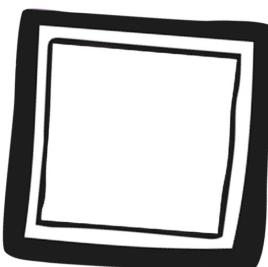
Capture your team's definition of the values below under a different lens. Note the lens you've used in the magnifying glass...











TEAM MEMBER ROLES

You are aiming to establish a core research team who are all going in the same direction based on a shared vision and values. Many research projects focus on the skills that individuals bring without considering whether team members have a compatible vision and values. This road-map invites you to dedicate time exploring together the philosophies and values that you share.

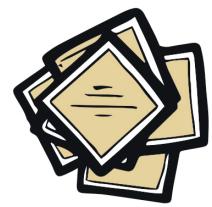
Contained in this resource is:

- / **A team member role map**
- / **Team member role cards, containing qualities and values of the role**
- / **Team member traits (animal cards)**

Conversations at an early point will help to avoid conflict later in the process. Particularly if you also agree processes to resolve challenges and the mechanisms that might help support with this process.

PROMPTS & ACTIVITIES

Turn the cards so that the description is facing you. Ask team members to identify which description they most relate to. Note down the number. Is there a second card that team members can relate to?



Turn the cards over and identify which roles you might be able to fill within this project. Using the Team Member Role Map you can make a note of where people fit within the framework and identify any gaps that you might have.

Questions you may wish to ask at this point in the process:

- / Do we have a good spread of roles?
- / Are there any gaps that we might need to fill?
- / How can we ensure that we continue to align to these roles?

PROMPTS & ACTIVITIES

We all have different traits as individuals. It's good to understand different personalities through our traits. One way to do this is through using the animal cards. Spread the cards out and ask the team members to identify which animal they can relate to. For example, the puppy is a loyal animal that is also very energetic, whilst the tortoise is an animal that takes his time, is considered but can win the race.



CAPTURE

As you are facilitating the activities, it's important that another team member is in charge of capturing the discussions and decisions.

For the team member role activities we have enclosed 3 worksheets to help in capturing an overview and to consider strategies for resolving conflict within the team:

- / **Team Member Role Map**
- / **I am...**
- / **Resolving challenges**

We suggest that you revisit and adjust your captured notes at every key team meeting to remind and realign the team. You can also re-run the activities to establish changes as a project progresses.

1. COMPLETER / FINISHER

(Organising tasks)

2. SHAPER

(Organising research aims and objectives)

3. PROBLEM SOLVER

(Organising context)

ORGANISING

3. Contribution

Having optimism and positive attitude towards challenges.

More innovative ideas might succeed.

Solves the practical issues of organising the research.

ORGANISING

2. Contribution

Empowers and inspires the team.

Understands the bigger picture.

Brings out the best in people.

Listens critically and shapes the research.

ORGANISING

1. Contribution

Gets things done.

Turns the team's ideas and concepts into practical actions and plans.

Pushes the team to make sure the work is completed on time.

5. MAKER/ EXPERIMENTER

(Building objects)

4. STORYTELLER

(Building narratives)

6. HUMANISER

(Building relationships)

7. EXPERIENCE PROTOTYPER

(Building experiences)

4. Contribution

Communicating someone's story with others in an imaginative way.

Evokes emotions through storytelling.

Putting other people in the heart of the conversation.

BUILDING

5. Contribution

Tests and re-tests potential scenarios to make ideas tangible.

Generates ideas.

Brings positive energy to the team.

Encourages creativity.

BUILDING

7. Contribution

Works between physical and digital platforms.

Makes things to generate and refine ideas.

Communicates ideas to others in a tangible, interactive way.

Has knowledge of various materials and making processes.

BUILDING

6. Contribution

Through empathy, a humaniser works to understand each individual participant and create a relationship.

Being the voice of other people when they are not there.

BUILDING

8. THEORY/ PRACTICE BRIDGER

(Learning from theory)

10. CROSS- POLLINATOR

(Learning from people)

9. CONTEXT- UTILISER

(Learning from context)

10. Contribution

Understands people with different perspectives, needs and expectations.

Draws associations and connections between seemingly unrelated ideas.

Has the ability to share inspiration with others.

LEARNING

8. Contribution

Is able to relate to a concept or theory and visualise how it might inform practice.

Understands theoretical positions from different disciplines.

Combines theories from different disciplines in a novel way to inform design research practice.

LEARNING

9. Contribution

Reframes a problem in a new way.

Understands context.

Seeks inspiration in unusual places.

Has experience in ethnographic practices.

LEARNING

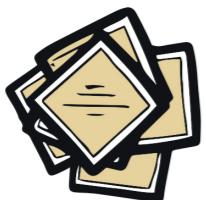
TEAM MEMBER ROLE MAP

CAPTURE

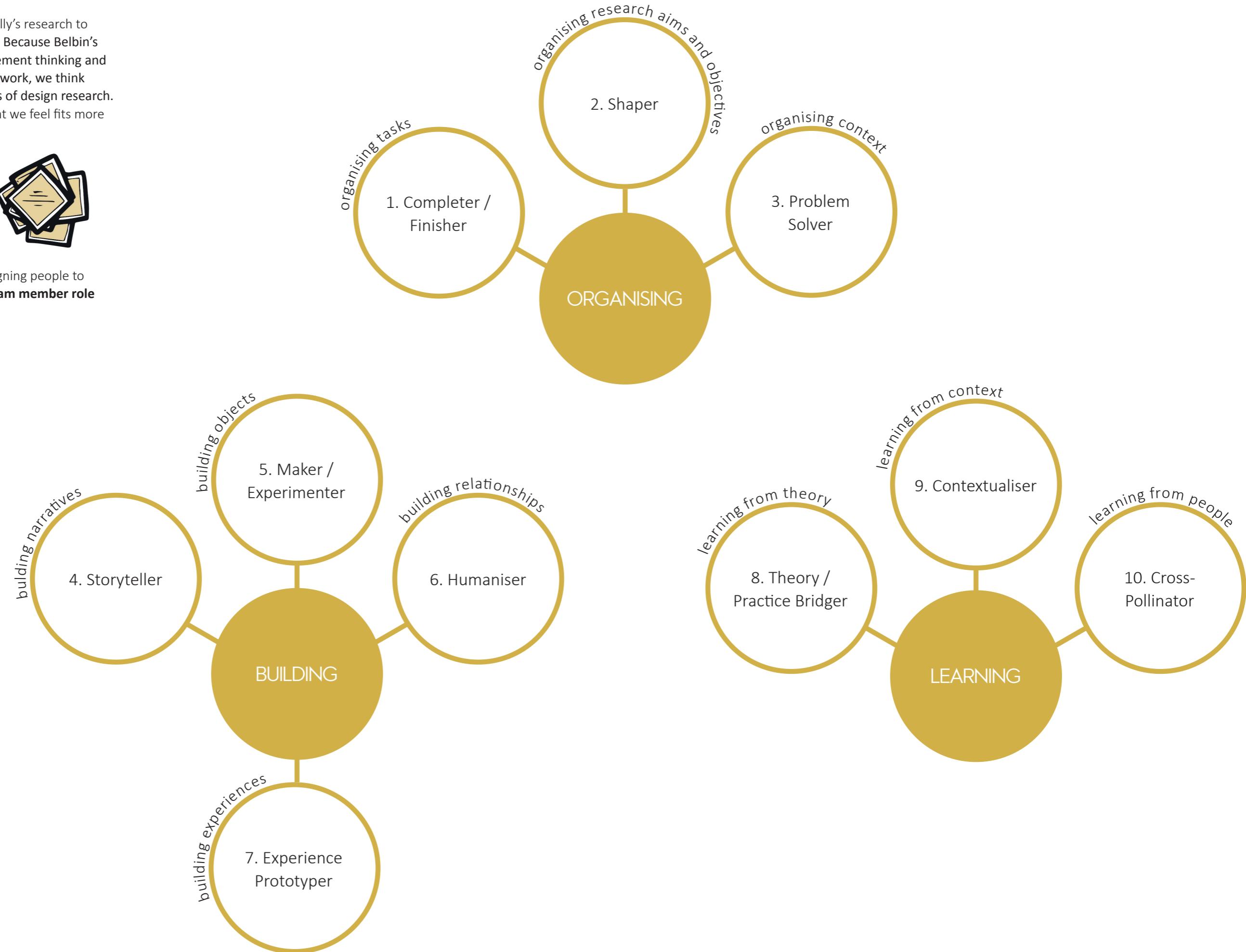
We were inspired by Belbin's and Kelly's research to create our **team member role map**. Because Belbin's categorisation derives from management thinking and Kelly's from a design thinking framework, we think there are still missing some features of design research. We created our team roles cards that we feel fits more with design research as a context.

The roles are catagorised by:

- **Organising**
- **Learning**
- **Building**



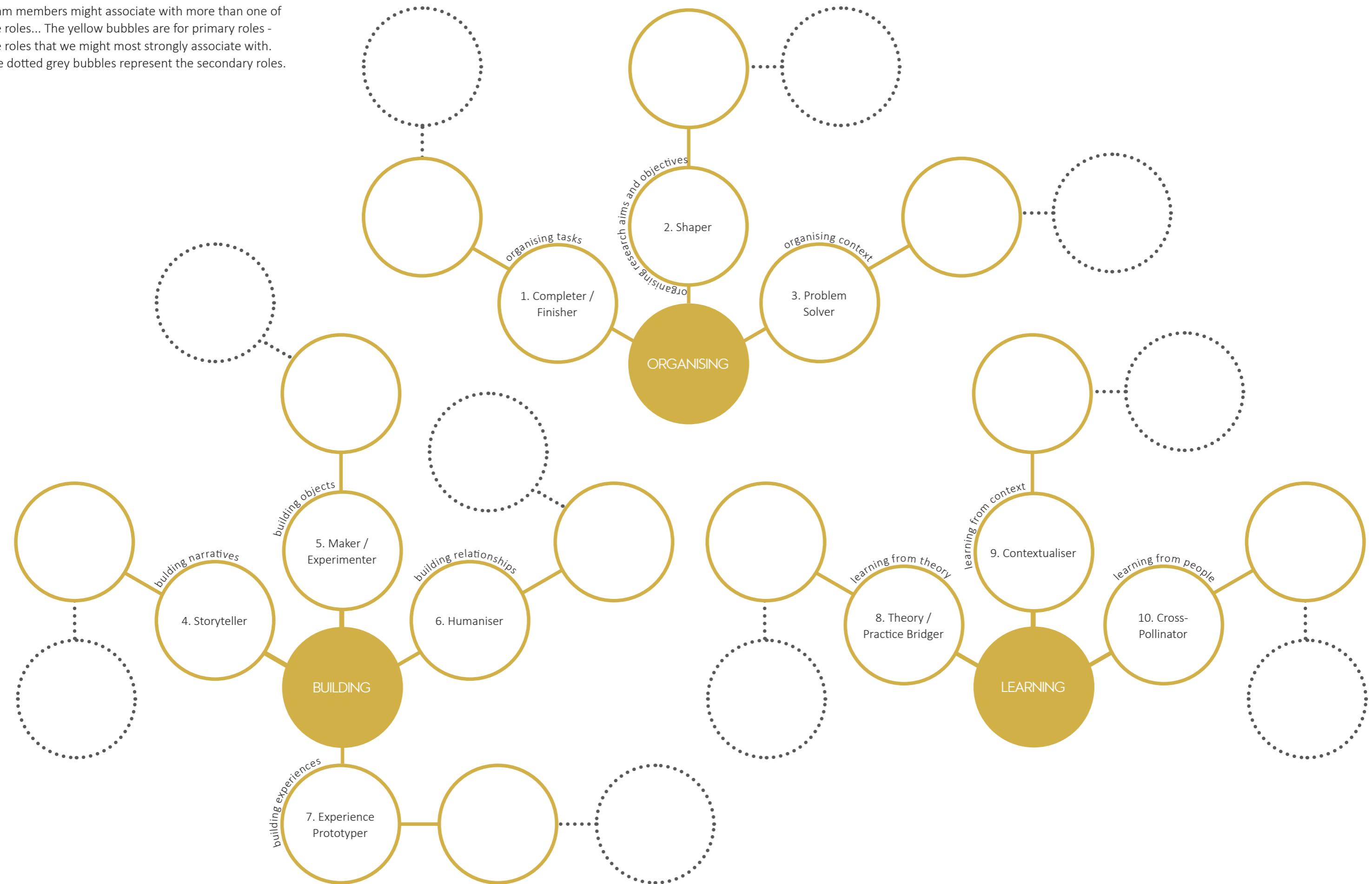
You can use this map for notes, assigning people to roles and in conjunction with the **team member role cards**.

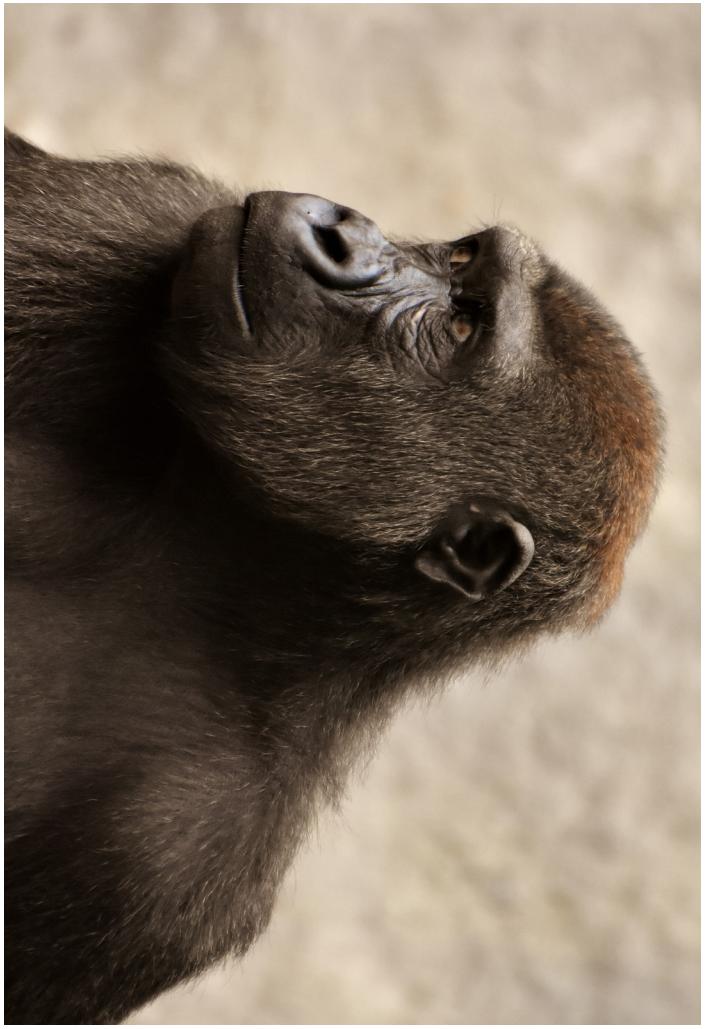
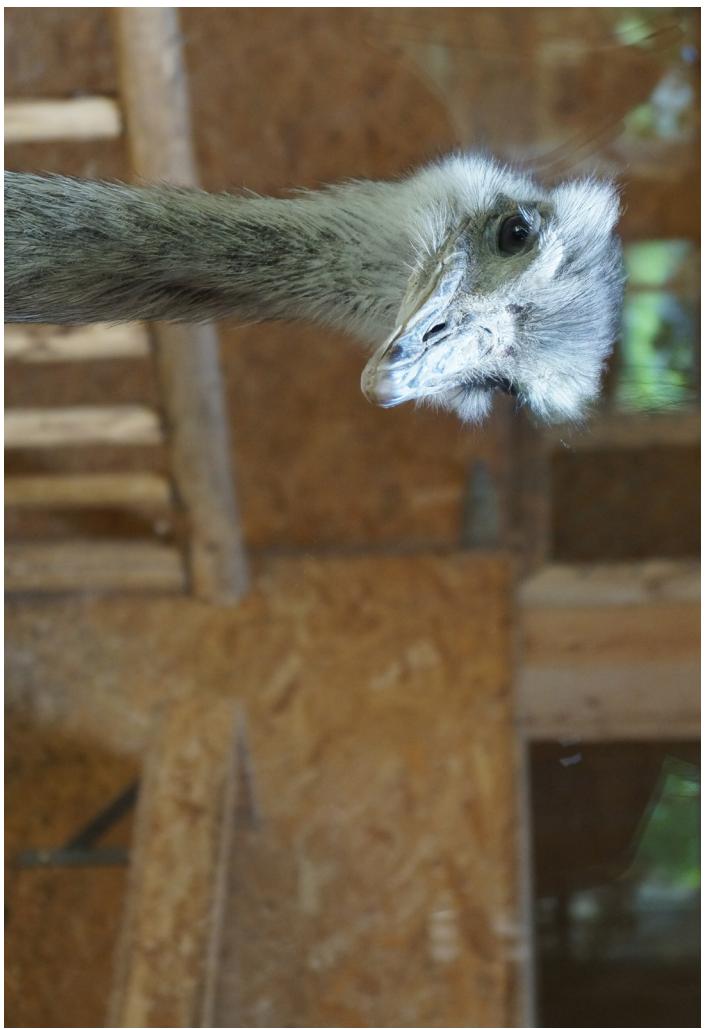


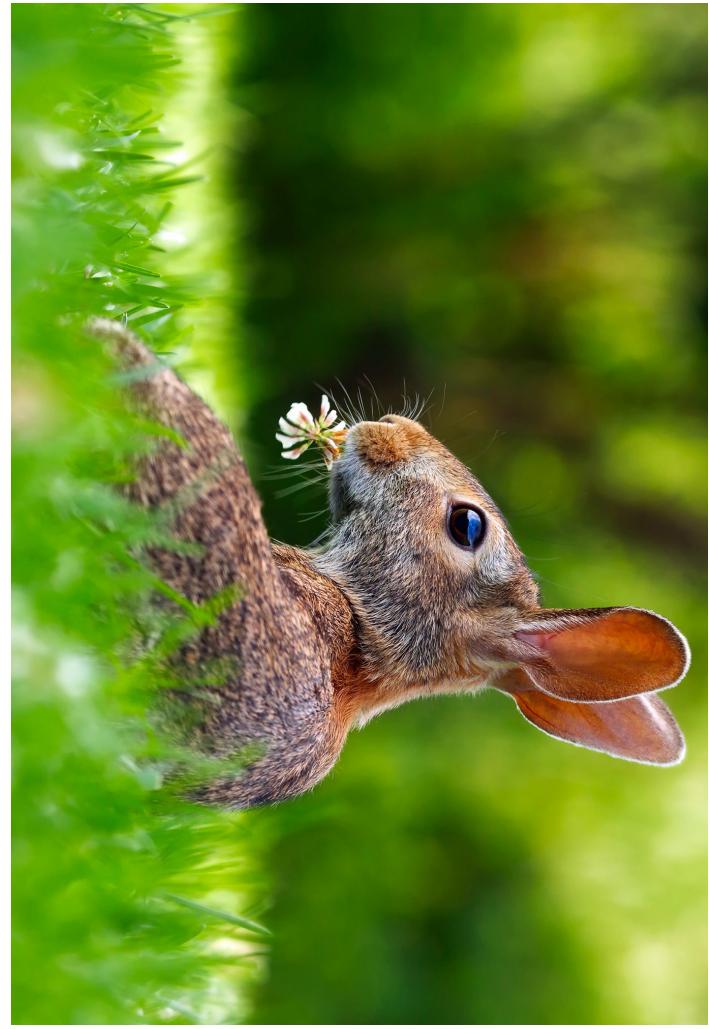
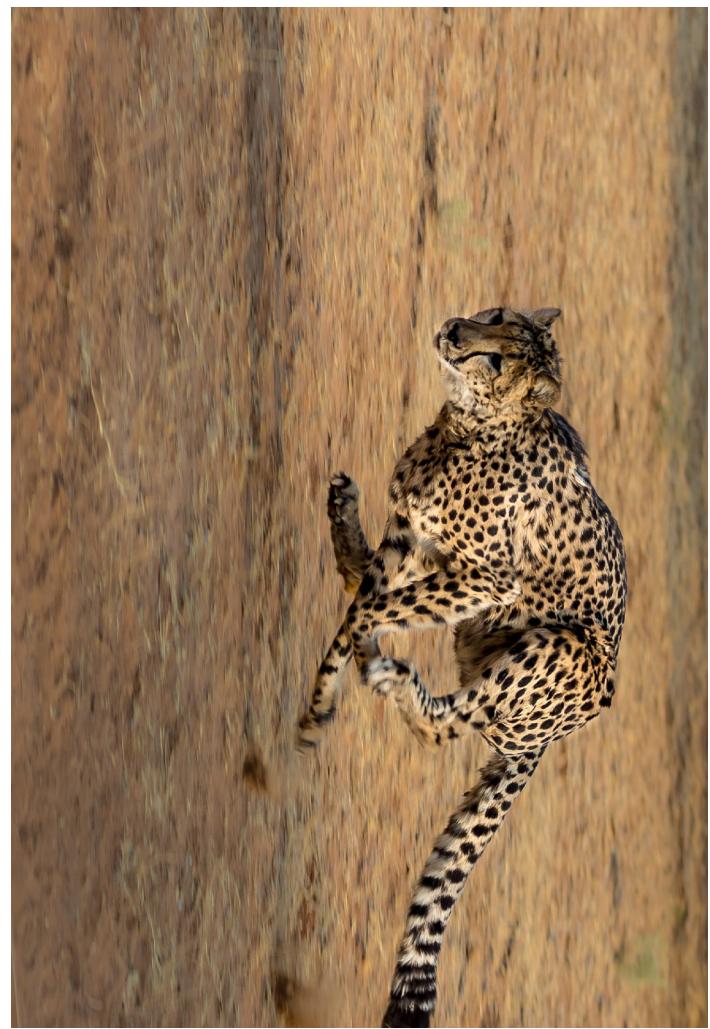
TEAM MEMBER ROLE MAP

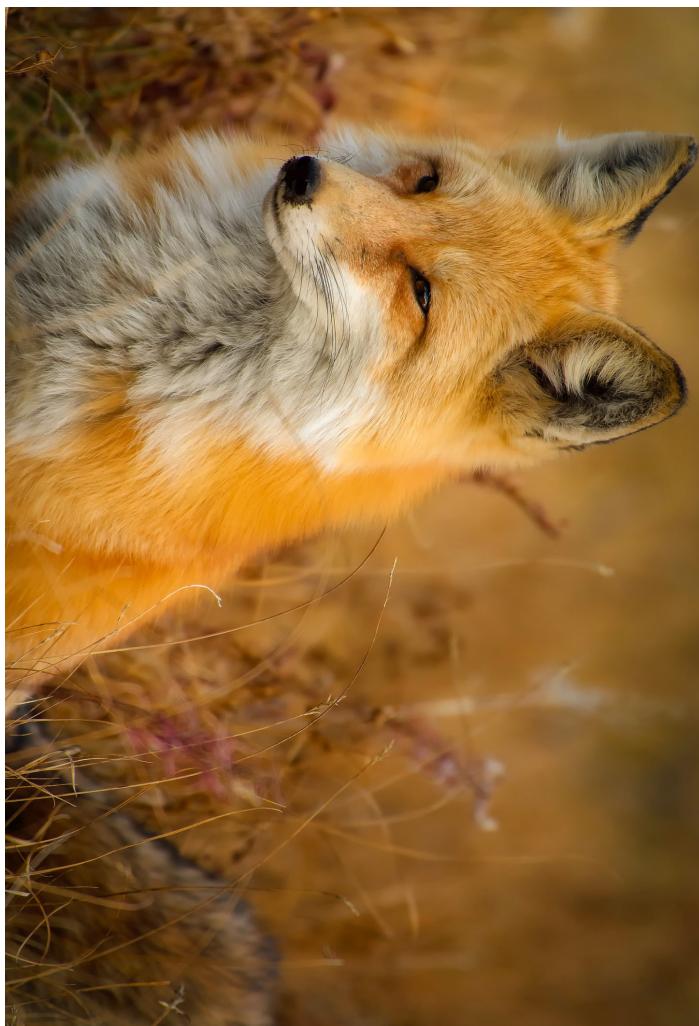
CAPTURE

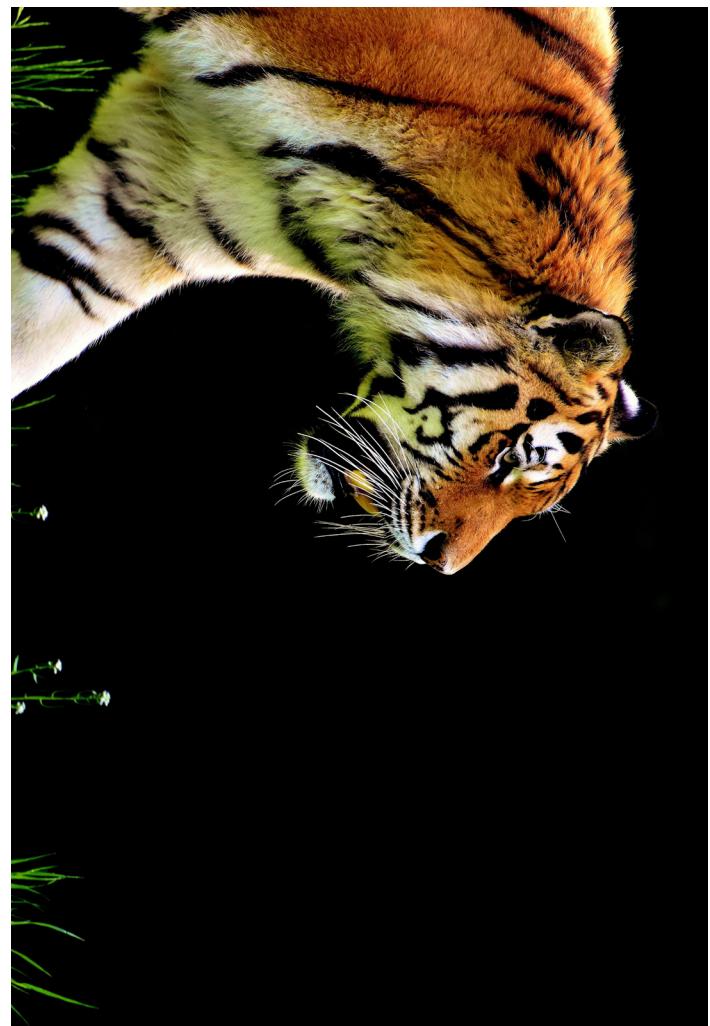
Team members might associate with more than one of the roles... The yellow bubbles are for primary roles - the roles that we might most strongly associate with. The dotted grey bubbles represent the secondary roles.

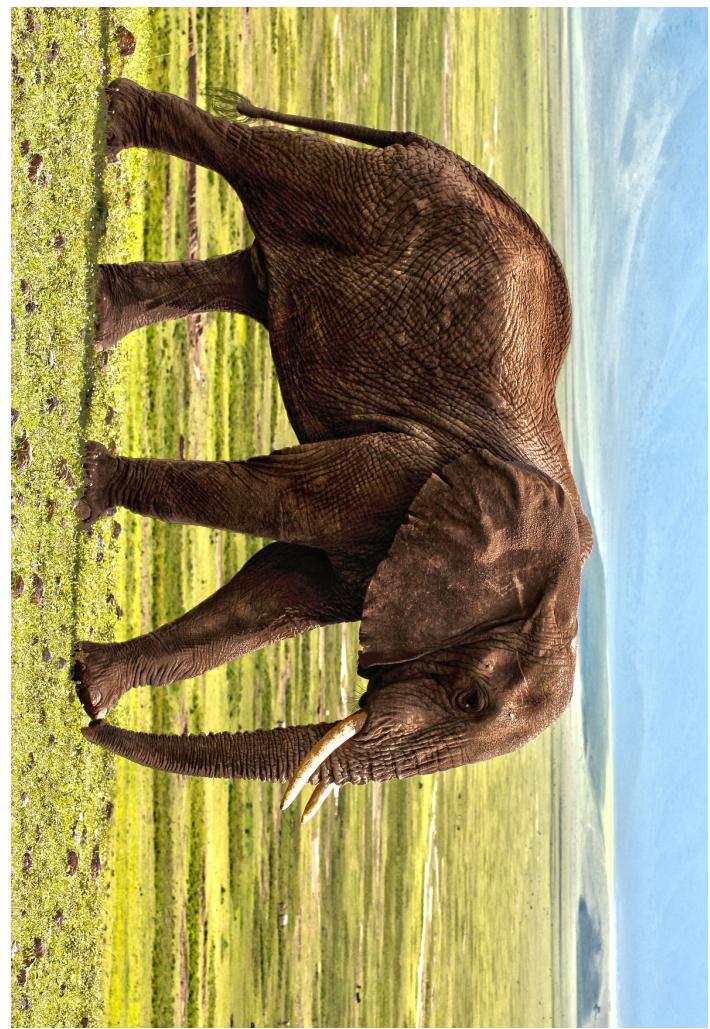
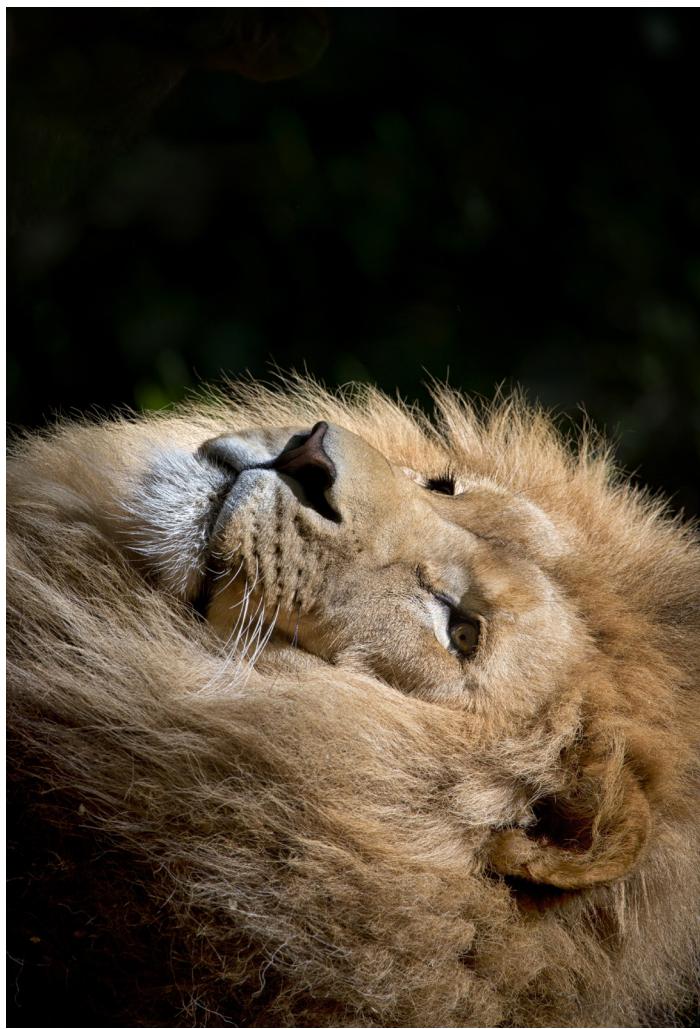












I AM...

CAPTURE

Here you can capture team members' traits against the animals.



Here you can capture team members' traits against the animals.



RESOLVING CHALLENGES

CAPTURE

Conflict within a team can either be a positive catalyst for change or something that is destructive. Spend some time in the group thinking about potential conflicts that might occur, and ways that you might resolve these.

BEHAVIOUR

Team member always dominating the conversation

CONSEQUENCES

Other team members feeling that they don't have a voice and valuable insights are lost

STRATEGY

Create agreed ground rules around turn-taking at the beginning of a meeting

MORAL QUALITIES

We have developed a set of moral quality cards, inspired by the 'Ethical Framework for the Counselling Professions (BACP)', but developed to fit more a design research context.

Reflect on the qualities described on the card and define these in your own words. Now turn the cards over and see if your definition corresponds to that on the back of the card.

As you come together as a team use the cards as talking points to identify those qualities you feel that you possess and qualities you would like to develop further.



PROMPTS & ACTIVITIES

You will find 4 provocation cards with questions such as: **What will empathy be in action? What will participation be in action?** As a team, explore what these mean to you within the context of your project. Can you use the moral quality cards as a response to these questions?



PROMPTS & ACTIVITIES

Finally look at ways you can support each other to build confidence in areas through socialisation and shadowing for example.

QUALITIES I POSSES	QUALITIES I WANT TO DEVELOP FURTHER	SUPPORT I NEED TO BUILD CONFIDENCE

CAPTURE

As you are facilitating the activities, it's important that another team member is in charge of capturing the discussions and decisions.

For the moral quality activities we have enclosed 2 worksheets to help in capturing an overview that can be referred to throughout your project:

- / **Qualities I possess...**
- / **In action...**

We suggest that you revisit and adjust your captured notes at every key team meeting to remind and realign the team. You can also re-run the activities to establish changes as a project progresses.

WHAT WILL
INTEGRITY
BE IN ACTION?

WHAT WILL
PARTICIPATION
BE IN ACTION?

COURAGE
TO LISTEN

LOVING LISTENING

A COMMITMENT TO GIVING
PARTICIPANTS THE SPACE/TIME TO
EXPRESS THEIR FEELINGS.

A COMMITMENT TO LISTEN
TO PARTICIPANTS' FEARS, CHALLENGES
AND FEELINGS AND BE SUPPORTIVE AND
NON-JUDGEMENTAL.

SPOTTING
CONCERN'S

WHAT WILL
SELF-CARE
BE IN ACTION?

TAILORING OUR
APPROACH

WHAT WILL
EMPATHY
BE IN ACTION?

A COMMITMENT TO A
PARTICIPANT'S SAFETY - LISTENING TO
THEIR CONCERN'S AND DIRECTING THEM
TO SOURCES OF HELP.

A COMMITMENT TO ACCEPTING
A PARTICIPANT'S VALUES.

ESTABLISHING
BOUNDARIES

BESPOKE
STRUCTURING

A COMMITMENT TO A TWO WAY RELATIONSHIP WITHIN BESPOKE BOUNDARIES. ESTABLISHING BOUNDARIES WHEN SHARING AN EXPERIENCE WITH PARTICIPANTS.

A COMMITMENT TO DEVELOP INDIVIDUALISED STRUCTURE AND APPROACH TO CONDUCT RESEARCH IN EFFECTIVE AND COMFORTABLE WAYS FOR THE PARTICIPANTS.

QUALITIES I POSSESS

QUALITIES I WANT TO
DEVELOP FURTHER

SUPPORT I NEED TO BUILD
CONFIDENCE

CRITICAL FRIENDS

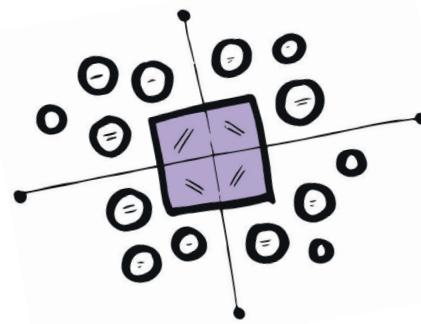
When you begin your research it can be difficult to anticipate possible ethical issues that might arise. Setting up a steering group of people from different walks of life, skills and experience to give you honest, constructive feedback will help with this process.

Make sure your critical friends include representatives from all your stakeholders including people who can benefit from your research as well as individuals who could be harmed by it. Using the **Critical Friend Map** can enable you to identify the types of knowledge and expertise you might require.

The map is categorised by people with:

- / Future implementation experience
- / Lived through experience
- / Personal knowledge
- / Knowledge of context

PROMPTS & ACTIVITIES

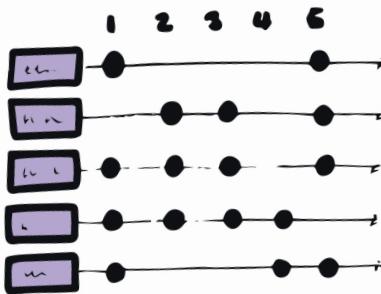


We have included a set of **Critical Friend Role Cards**. It's important to find out how these critical friends might want to be involved. As an activity, ask the critical friends to define their role and what they would like to contribute to the project.



PROMPTS & ACTIVITIES

Some critical friends might want to be more, or less involved during different milestones of the project. The project itself may also require different critical friends at different times. We have included a **Milestones Map** to enable you to start to think about when different people are likely to be involved. This can be used with your critical friends or as a team exercise. Naturally, this may alter over the duration of the project.



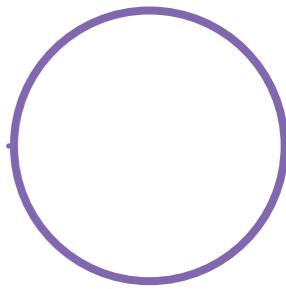
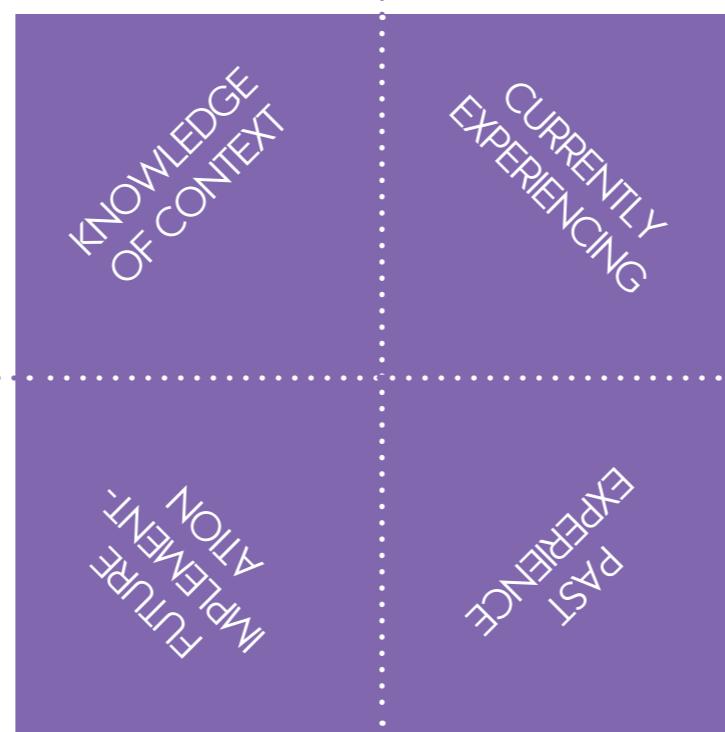
CAPTURE

As you are facilitating the activities, it's important that another team member is in charge of capturing the discussions and decisions.

For the critical friend activities we have enclosed 2 worksheets to help in capturing an overview that can be referred to throughout your project:

- / **Critical Friend Map**
- / **Milestone Map**

We suggest that you revisit and adjust your captured notes at every key team meeting to remind and realign the team. You can also re-run the activities to establish changes as a project progresses.



CRITICAL FRIEND MAP

CAPTURE

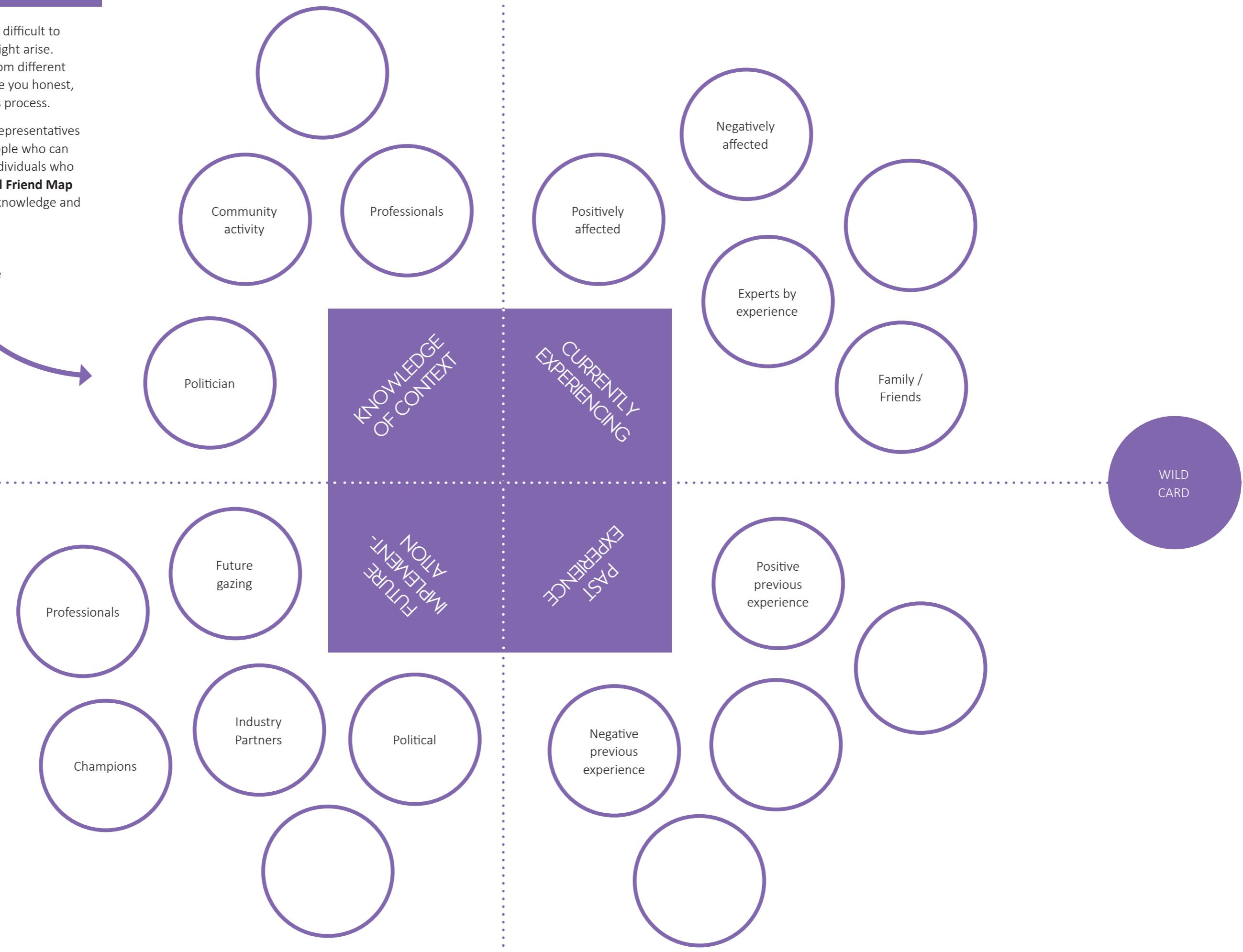
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Make sure your critical friends include representatives from all your stakeholders including people who can benefit from your research as well as individuals who could be harmed by it. Using the **Critical Friend Map** can enable you to identify the types of knowledge and expertise you might require.

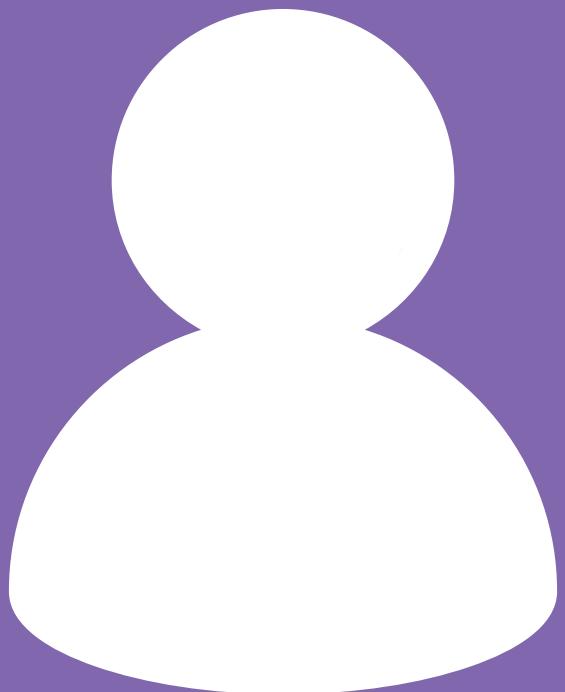
The map is categorised by people with:

- Future implementation experience
- Lived through experience
- Personal knowledge
- Knowledge of context

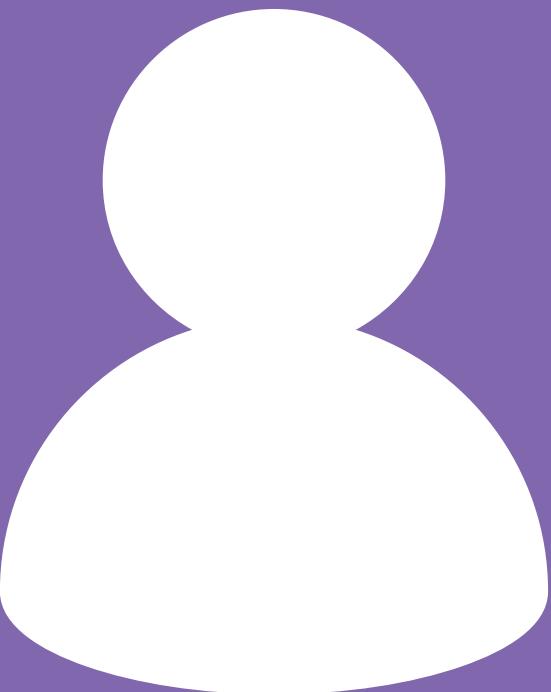
Use the reverse of this to create your map including potential names and contact details.



NAME:

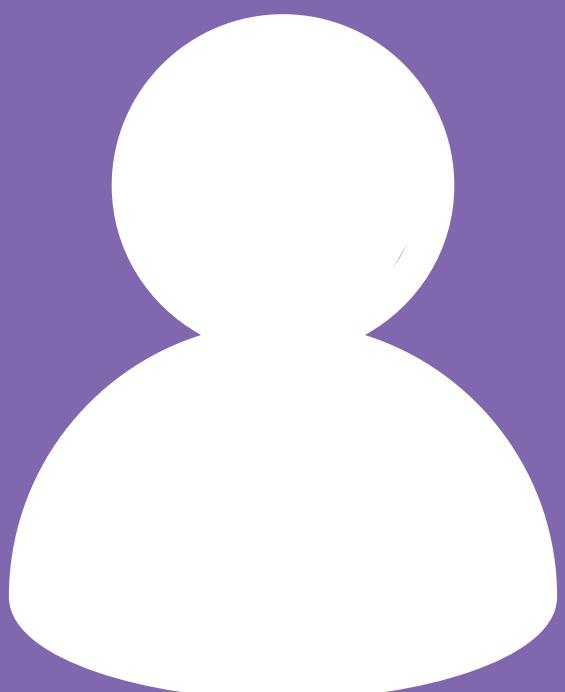


NAME:

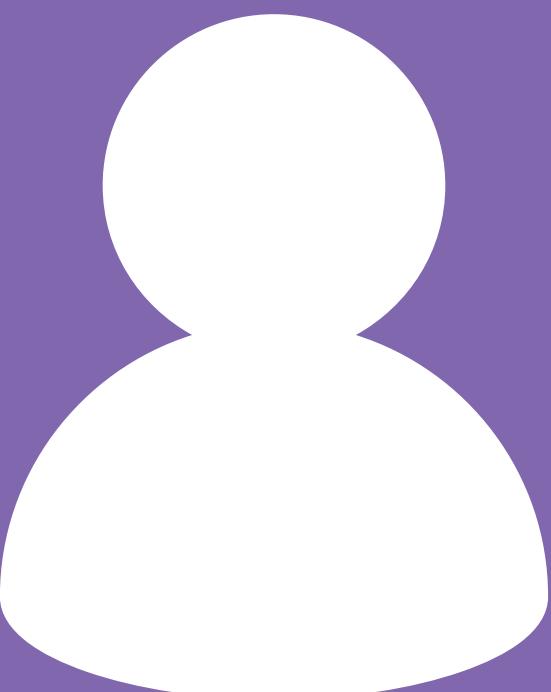


ROLE:

NAME:



NAME:



ROLE:

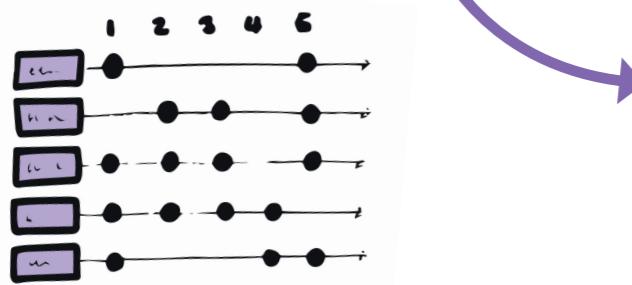
I WOULD LIKE TO CONTRIBUTE:

CRITICAL FRIENDS ▾

CRITICAL FRIEND MILESTONES

Some critical friends might want to be more, or less involved during different milestones of the project. The project itself may also require different critical friends at different times. This is a **Milestones Map** to enable you to start to think about when different people are likely to be involved. This can be used with your critical friends or as a team exercise. Naturally, this may alter over the duration of the project.

Add your critical friends to the left hand column and the project milestones along the top, then plot their involvement along the dotted lines with stickers, or postits. Here's an example for you to follow.



MILESTONES >

A

B

C

D

E

F

G

CAPTURE

CRITICAL FRIENDS ▾

Politician



Industry Partner



Experts by experience



Positive previous experience



Champion 1



Champion 2



Negative previous experience

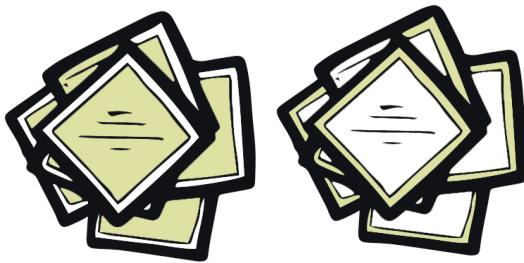


Future gazing



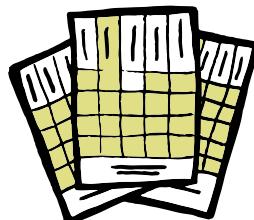
INFORMEDNESS OF CONSENT

One of the bed rocks of ethical practice is informed consent. This means that individuals who agree to participate in any element of the research are aware that they are agreeing to this and they are clear as to the purpose of the study and their role within it. It is therefore essential that as researchers we are aware of a person's capacity to understand what is been asked of them and to find ways to represent and convey information about the study as clearly as possible.



PROMPTS & ACTIVITIES

To capture more detail about a participant's level of consent we've included some consent postcards. These can be used at each research activity for participants to express their level of consent relating to photographs, videos, audio recordings and quotations.



For other examples of visual, interactive methods of gaining informed look at:

- / Jet Gipsen
www.ethicsfordesigners.com
- / Cara Broadley, Visual Questionnaire
www.carabroadley.weebly.com

PROMPTS & ACTIVITIES

Things to think about:

- / How do you inform somebody about the project?
- / How often do you share how you will engage with them? Do you need informed consent every time you meet the participant?
- / What is the format of the consent form? What is the language? The layout? How does it look?
- / How can we create something that can be iterative? (Not an A4 sheet)

We've included a set of cards that list the potential methods of enquiry and outcomes that might occur in a research project. Use these to have general conversations with participants selecting the ones that they consent to.

CAPTURE

As you are facilitating the activities, it's important that another team member is in charge of capturing the discussions and decisions. For the informedness of consent activities we have enclosed 3 worksheets to help in capturing an overview that can be referred to throughout your project:

- / **Method of enquiry**
- / **Outcomes**
- / **Consent postcards**

We suggest that you revisit and adjust your captured notes at every key team meeting to remind and realign the team. You can also re-run the activities to establish changes as a project progresses.

INTERVIEW

MAKING

ETHNOGRAPHY

SURVEY /
QUESTIONNAIRE



[PRINT SINGLE SIDED
AND CUT]

WORKSHOP

OBSERVATION

CONVERSATION



[PRINT SINGLE SIDED
AND CUT]

JOURNAL
PAPER

WEBSITE

CONFERENCE

EXHIBITION

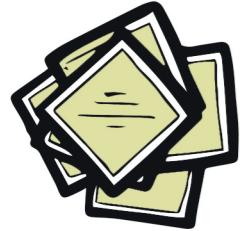


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AND CUT]

METHOD OF ENQUIRY

CAPTURE

Use the method cards to highlight how you might interact with research participants and brainstorm ways to gain informed consent.



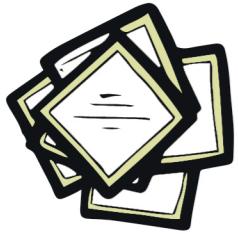
Add this to a digital document by photographing



OUTCOMES

CAPTURE

Use the outcome cards to highlight how you might like to present your research findings and brainstorm ways to gain informed consent.



Add this to a digital document by photographing



DATE / ACTIVITY

No consent
Consent to share within team
Consent to share anonymously
Consent to share including name
Consent to use as promotional or future funding / research

PHOTOS

DATE / ACTIVITY

No consent
Consent to share within team
Consent to share anonymously
Consent to share including name
Consent to use as promotional or future funding / research

VIDEOS

DATE / ACTIVITY

No consent
Consent to share within team
Consent to share anonymously
Consent to share including name
Consent to use as promotional or future funding / research

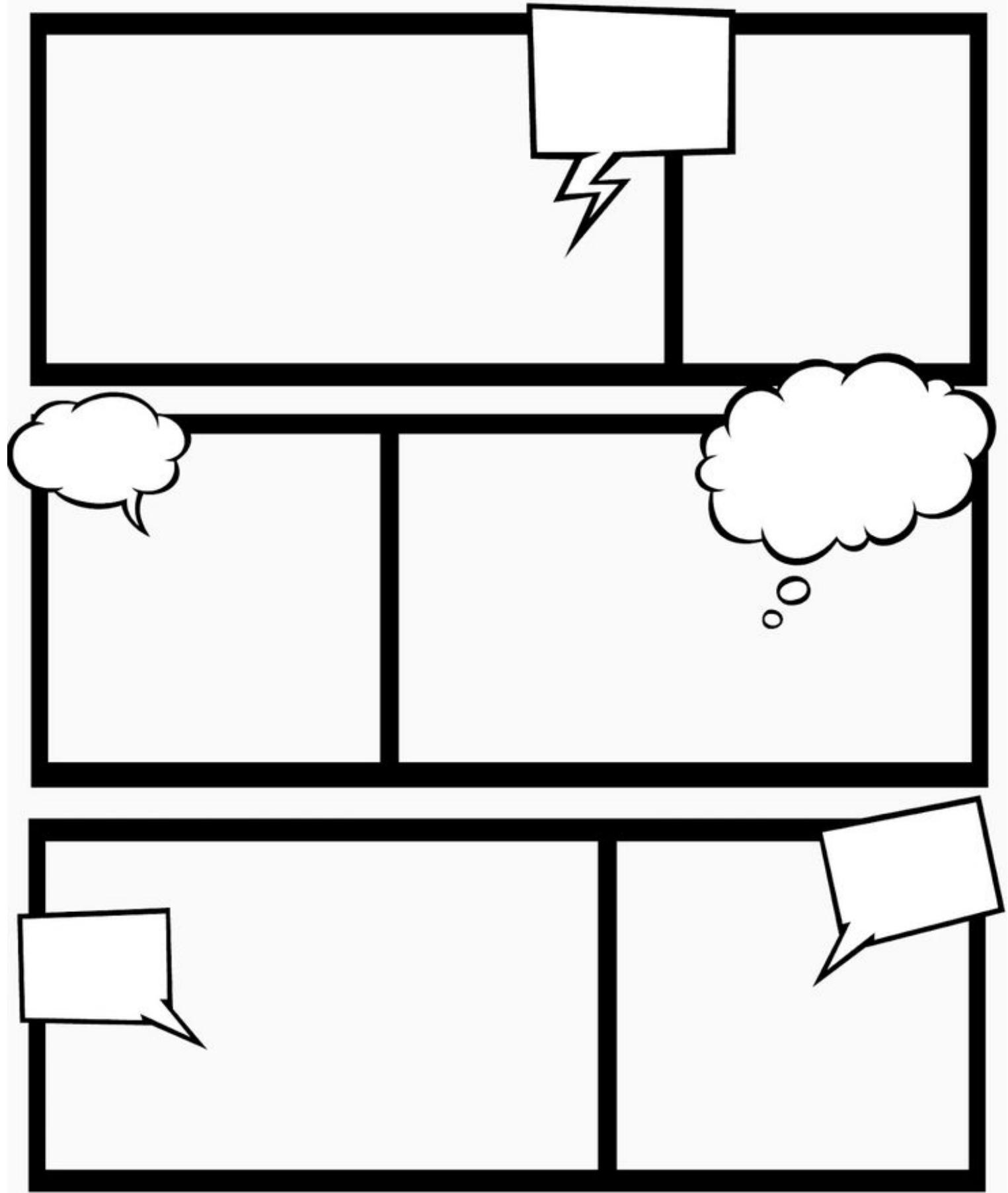
AUDIO RECORDINGS

DATE / ACTIVITY

No consent
Consent to share within team
Consent to share anonymously
Consent to share including name
Consent to use as promotional or future funding / research

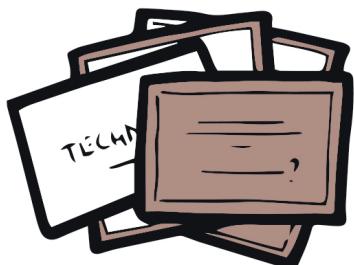
QUOTATIONS

JOURNEY OF CONSENT



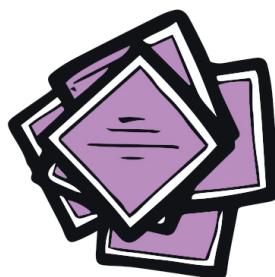
PROVOCATIONS

The purpose of the provocation cards is to start discussions between the team members on ethical concerns or issues arising from working with potentially vulnerable groups of participants. The selected provocation cards may make team members think about the research context more broadly and/or align new members with the thinking and values of the existing team. Think about them as “wild cards” in games.



PROMPTS & ACTIVITIES

The prompt cards work well with the value cards and when discussing what we can and cannot do within a research project. We've enclosed another one of these worksheets to help capture discussions.



PROMPTS & ACTIVITIES

Pick up a card and discuss it with your team at any point of the research programme. Try and find some common ground in the situations described in the cards. What would you do? How would you tackle the issue?

The cards are divided in four categories:

- / **Technology**
- / **Sense of Self**
- / **Relationship between researchers and participants**
- / **Relationships between family members**

If you find that your team is quite technology minded, you might want to choose a different section of the pack to challenge thinking.

CAPTURE

As you are facilitating the activities, it's important that another team member is in charge of capturing the discussions and decisions. For the provocation activities we have enclosed 1 worksheet to help in capturing an overview that can be referred to throughout your project:

- / **We can / we cannot**

We suggest that you revisit and adjust your captured notes at every key team meeting to remind and realign the team. You can also re-run the activities to establish changes as a project progresses.

TECHNOLOGY

[provocations]

TECHNOLOGY

[provocations]

TECHNOLOGY

[provocations]

TECHNOLOGY

[provocations]

YOU HAVE BEEN GIVEN PERMISSION
TO USE DATA FOR A YEAR BUT YOU
STILL NEED THE DATA.

WHAT DO YOU DO?

SOMEBODY STEALS DATA
FROM PROTOTYPES.

WHAT DO YOU DO?

YOU HAVE PERMISSION TO USE
SOMEBODY'S DATA AFTER HIS DEATH.
HOW LONG SHOULD YOU KEEP IT?

YOU USE OPEN SOURCE SOFTWARE
TO MAKE A NEW PROTOTYPE.
AFTER THE PROJECT SOMEBODY
ASKS TO BUY THE IDEA.

CAN YOU SELL IT?

A PARTICIPANT SHARES A PRIVATE POST WITH YOU.

CAN YOU USE IT IN THE RESEARCH?

A PARTICIPANT HAS ACCESS TO HER DECEASED DAUGHTER'S PRIVATE ACCOUNTS.

SHOULD YOU USE THE DATA?

YOU HAVE REALLY USEFUL DATA FROM AN OLD PROJECT.

COULD YOU USE IT IN A NEW PROJECT?

A PROTOTYPE IS HELPING A FAMILY WITH THE GRIEVING PROCESS BUT THEY ACCIDENTALLY BREAK IT?

WHAT SHOULD YOU DO NEXT?

A PARTICIPANT DOESN'T RECOGNISE
PHOTOS FROM HIS OWN CHILDHOOD.

WHAT DO YOU SAY?

SENSE OF SELF

[provocations]

PARTICIPATION IN RESEARCH IS HARMING
THE PARTICIPANT'S HEALTH BUT SHE STILL
WANTS TO TAKE PART IN THE RESEARCH.

WHAT DO YOU DO?

A PARTICIPANT DOESN'T THINK THEY HAVE
DEMENTIA BUT SHE HAS BEEN DIAGNOSED
WITH IT.

WOULD YOU INVOLVE THEM IN A
DEMENTIA STUDY?

YOU ARE WORKING WITH
PARTICIPANTS TO MAKE MEANINGFUL
OBJECTS THAT MIGHT HELP OTHER
PEOPLE IN THE FUTURE.

WHO OWNS THE IDEAS?

A PARTICIPANT IS ASKING YOU
TO USE LIVING TISSUE FROM ONE
OF THE OBJECTS.

WHAT WOULD YOU DO?

A PARTICIPANT ASKS YOU FOR ADVICE
ABOUT HER MEDICATION.

WHAT WOULD YOU SAY?

A PARTICIPANT IS GOING TO
COMMIT A CRIME.

WHAT WOULD YOU DO?

YOU BECAME VERY FRIENDLY WITH THE
PEOPLE YOU WORK WITH.

WOULD THAT BE OK?

RELATIONSHIPS BETWEEN RESEARCHERS AND PARTICIPANTS

[provocations]

A PARTICIPANT DOESN'T WANT TO CONTINUE TAKING PART IN THE RESEARCH BUT SHE WANTS TO CONTINUE HAVING INFORMAL MEETINGS WITH THE RESEARCHER.

WHAT WOULD YOU DO?

A PARTICIPANT'S LIFE EXPECTANCY IS MUCH SHORTER THAN THE PROJECT, WOULD YOU INVOLVE THEM IN THE RESEARCH IF THEY WANT TO TAKE PART?

AT THE END OF THE RESEARCH, SOME OF THE PARTICIPANTS ASKED TO KEEP THE OBJECTS THAT WERE MADE FOR THEM.

WHAT WOULD YOU DO?

YOUR COLLEAGUES SAID THAT YOU ARE GETTING TOO CLOSE TO YOUR PARTICIPANTS.
WHAT WOULD YOU DO NEXT?

A PARTICIPANT IS ASKING YOU
TO HELP THEM DIE.
WHAT SHOULD YOU SAY?

HOW WOULD YOU KEEP IN CONTACT
WITH SOMEBODY WHO IS BEREAVED?

THE FAMILY OF THE PARTICIPANTS
WOULD LIKE TO SHARE SOME PHOTOS
BUT THE PARTICIPANT DOESN'T WANT
THEM TO BE SHARED.
WHAT DO YOU DO?

RELATIONSHIPS BETWEEN FAMILY MEMBERS

[provocations]

A PARTICIPANT WITH DEMENTIA DOESN'T REMEMBER WHY HE IS PART OF A RESEARCH PROCESS.

WHAT DO YOU DO?

A BEREAVED MOTHER FOUND HER DAUGHTER'S DIARY AND SHE WANTS TO USE PARTS OF IT WITHIN THE RESEARCH.

WHAT DO YOU DO?

A PARTICIPANT HAS A TERMINAL ILLNESS AND SHE IS ASKING YOU TO MAKE AN OBJECT THAT WILL SAVE HER.

WHAT DO YOU DO?

A PARTICIPANT'S WISH IS TO BE REMEMBERED AFTER HIS DEATH AND HE ASKED THE RESEARCHER TO KEEP HIS DATA FOREVER.

SHOULD YOU AGREE?

TWO FAMILY MEMBERS DISLIKE EACH OTHER BUT WANT TO BE PART OF THE SAME WORKSHOP.

WHAT WOULD YOU DO?

NOT ALL OF THE FAMILY WANTS TO PARTICIPATE IN THE RESEARCH.

WHAT DO YOU DO?

A PARTICIPANT WANTS YOU TO HELP HIM CONTACT HIS DEAD RELATIVE.

WHAT WOULD YOU DO?

PROVOCATIONS

CAPTURE

During this exercise you will discuss activities that you can and cannot do within this project which relate to your values. Make a note of them here and refer to them during team meetings - add to them, change them!

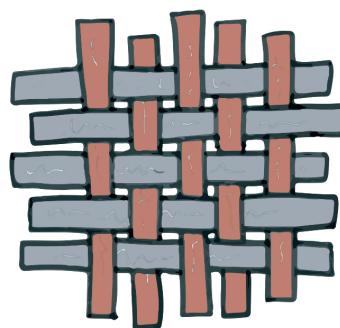
WE CAN

WE CANNOT

WARP & WEFT

One of the limitations of existing approaches to ethics is that the process itself leaves very little room for negotiation in terms of what participants need to enable them to feel comfortable and to have a sense of agency within the process. If we are to move from a position of researching on people, to research with people, we need to develop methods to allow individuals to have a voice in the development of ethics protocols.

You may choose and develop statements relating to what your participants, team members and stakeholders would and would not like to happen during the research process.

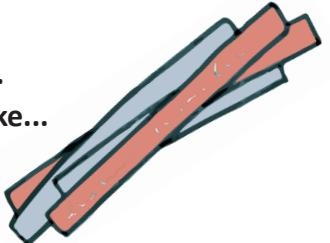


PROMPTS & ACTIVITIES

Using the warp & weft strips of paper, encourage research participants, team members and critical friends to write their statements surrounding what they would and would not like to happen during the research process.

Blue strips = I would like...

Red strips = I would not like...



These statements can be woven together like the warp and weft when creating a tapestry. This can be added to throughout the project and shared with everyone in the team.

PROMPTS & ACTIVITIES

During this exercise you will discuss activities that you can and cannot do within this project which relate to your values. Make a note of them on the capture sheet and refer to them during team meetings - add to them, change them!

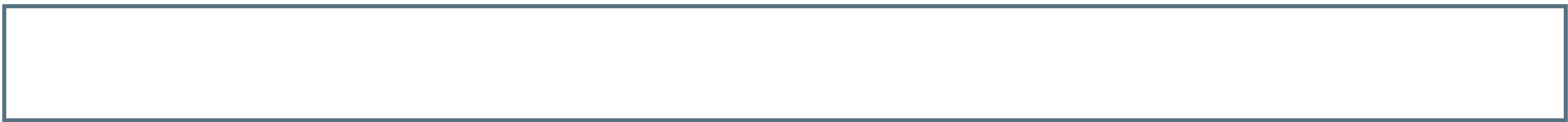
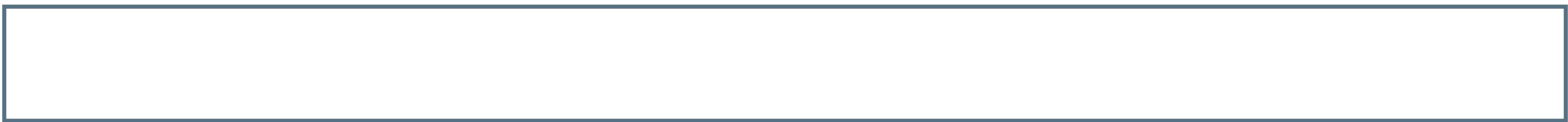
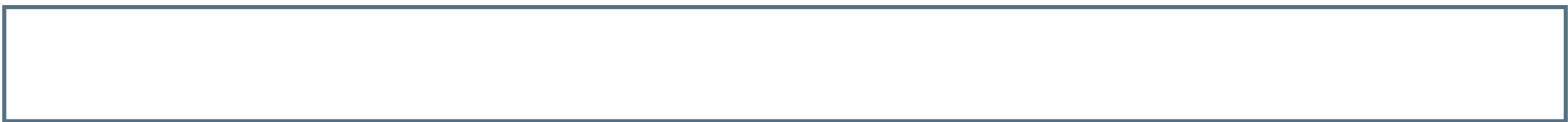
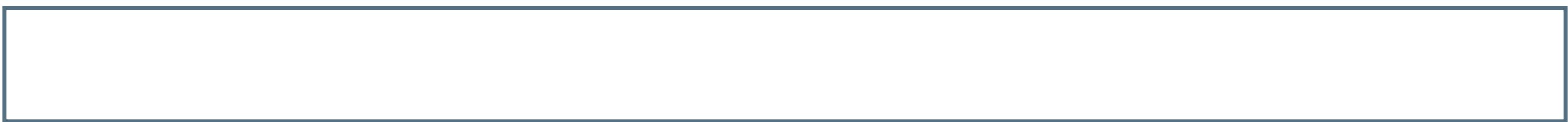
WE CAN

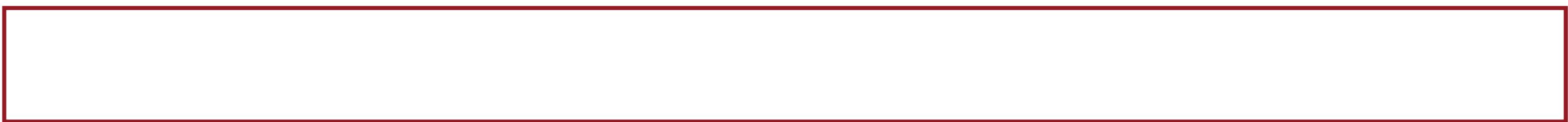
WE CANNOT

CAPTURE

As you are facilitating the activities, it's important that another team member is in charge of capturing the discussions and decisions. We would suggest capturing the statements on the worksheet as well as on the paper strips. We've enclosed a Warp and Weft worksheet for this purpose.

We suggest that you revisit and adjust your captured notes at every key team meeting to remind and realign the team. You can also re-run the activities to establish changes as a project progresses.





During this exercise you will discuss activities that you can and cannot do within this project which relate to your values. Make a note of them here and refer to them during team meetings - add to them, change them!

WE CAN

WE CANNOT

GLOSSARY OF TERMS

Accountability: taking personal responsibility for one's conduct.

Adverse event (AE): a medically undesirable event occurring in a research subject, such as an abnormal sign, symptom, worsening of a disease, injury, etc. A serious adverse event (SAE) results in death, hospitalization (or increased hospital stay), persistent disability, birth defect, or any other outcome that seriously jeopardizes the subject's health.

Amendment: a change to a research protocol approved by an institutional review board

Audit: a formal review of research records, policies, activities, personnel, or facilities to ensure compliance with ethical or legal standards or institutional policies. Audits may be conducted regularly, at random, or for-cause (i.e. in response to a problem).

Autonomy: A philosophical term meaning self-governance whereby one has the right, power or condition of self-governance. The individual has self-determination and freedom from external control or coercion.

Beneficence: the ethical obligation to do good and avoid causing harm.

Bioethics: the study of ethical, social, or legal issues arising in biomedicine and biomedical research.

Clinical trial: an experiment designed to test the safety or efficacy of a type of therapy (such as a drug).

Code of ethics: Defines the core values of the field and provides guidance for what professionals should do when they encounter conflicting obligations or responsibilities in their work.

Cognitive dissonance: The cognitive process whereby individual's values and beliefs are challenged. The challenging process is necessary in moral reasoning to wrestle with moral dilemmas.

Collaboration agreement: an agreement between two or more collaborating research groups concerning the conduct of research. The agreement may address the roles and responsibilities of the scientists, access to data, authorship, and intellectual property.

Commercialization: the process of developing and marketing commercial products (e.g. drugs, medical devices, or other technologies) from research.

Community review: a process for involving a community in the review of research conducted on members of the community. Some research studies include community advisory boards as a way of involving the community.

Confidentiality: the obligation to keep some types of information confidential or secret. In science, confidential information typically includes: private data pertaining to human subjects, papers or research proposals submitted for peer review, personnel records,

proceedings from misconduct inquiries or investigations, and proprietary data.

Conflict of interest (COI): a situation in which a person has a financial, personal, political or other interest which is likely to affect his or her judgment or decision-making concerning the performance of his or her ethical or legal obligations or duties.

consequentialism: an approach to ethics where right and wrong are based on the greater amount of good. The consequences of action play a major role in deciding the greater amount of good.

Data management: Practices and policies related to recording, storing, auditing, archiving, analyzing, interpreting, sharing, and publishing data.

Deontic ethics (non-consequential): an ethical theory based on the ideal that we can perceive rightness apart from any consequences. This perspective believes that there is an inherent right, which must be followed regardless of any extraneous factors. Right and wrong are based on the ideal of what should be.

Ethical dilemma: A situation in which two or more potential actions appear to be equally justifiable from an ethical point of view, i.e. one must choose between the lesser of two evils or the greater of two goods.

Ethical reasoning: Making a decision in response to a moral dilemma based a careful and thorough assessment of the

different options in light of the facts and circumstances and ethical considerations.

Ethical relativism: The view that ethical standards are relative to a particular culture, society, historical period, etc.

Ethics (or morals): 1. Standards of conduct (or behaviour) that distinguish between right/wrong, good/bad, etc. 2. The study of standards of conduct.

Helsinki Declaration: ethical guidelines for conducting medical research involving human subjects research adopted by the World Medical Association.

Honesty: the ethical obligation to tell the truth and avoid deceiving others.

Informed consent: the process of making a free and informed decision (such as to participate in research). Individuals who provide informed consent must be legally competent and have enough decision-making capacity to consent to research. Research regulations specify the types of information that must be disclosed to the subject.

Intellectual property: legally recognized property pertaining to the products of intellectual activity, such as creative works or inventions. Forms of intellectual property include copyrights on creative works and patents on inventions.