

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 group 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

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

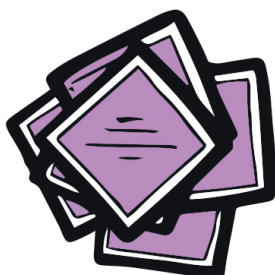
The cards are divided in four categories:

- / **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.

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.



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**

If you need extra copies of these, please download them from www.enablingongoingness.com

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

CAN YOU SELL IT?

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

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

SHOULD YOU USE THE DATA?

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

WHAT SHOULD YOU DO NEXT?

A PARTICIPANT SHARES A PRIVATE
POST WITH YOU.

CAN YOU USE IT IN THE RESEARCH?

YOU HAVE REALLY USEFUL DATA
FROM AN OLD PROJECT.

COULD YOU USE IT IN A NEW PROJECT?

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

WHAT DO YOU SAY?

SENSE OF SELF

[provocations]

SENSE OF SELF

[provocations]

SENSE OF SELF

[provocations]

SENSE OF SELF

[provocations]

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

WOULD YOU INVOLVE THEM IN A
DEMENTIA STUDY?

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

WHAT DO YOU DO?

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]

RELATIONSHIPS
BETWEEN RESEARCHERS
AND PARTICIPANTS

[provocations]

RELATIONSHIPS
BETWEEN RESEARCHERS
AND PARTICIPANTS

[provocations]

RELATIONSHIPS
BETWEEN RESEARCHERS
AND PARTICIPANTS

[provocations]

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

WHAT WOULD YOU DO?

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?

YOUR COLLEAGUES SAID THAT YOU
ARE GETTING TOO CLOSE TO YOUR
PARTICIPANTS.

WHAT WOULD YOU DO NEXT?

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

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]

RELATIONSHIPS
BETWEEN FAMILY
MEMBERS

[provocations]

RELATIONSHIPS
BETWEEN FAMILY
MEMBERS

[provocations]

RELATIONSHIPS
BETWEEN FAMILY
MEMBERS

[provocations]

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

WHAT DO KEEP REMINDING THEM?

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