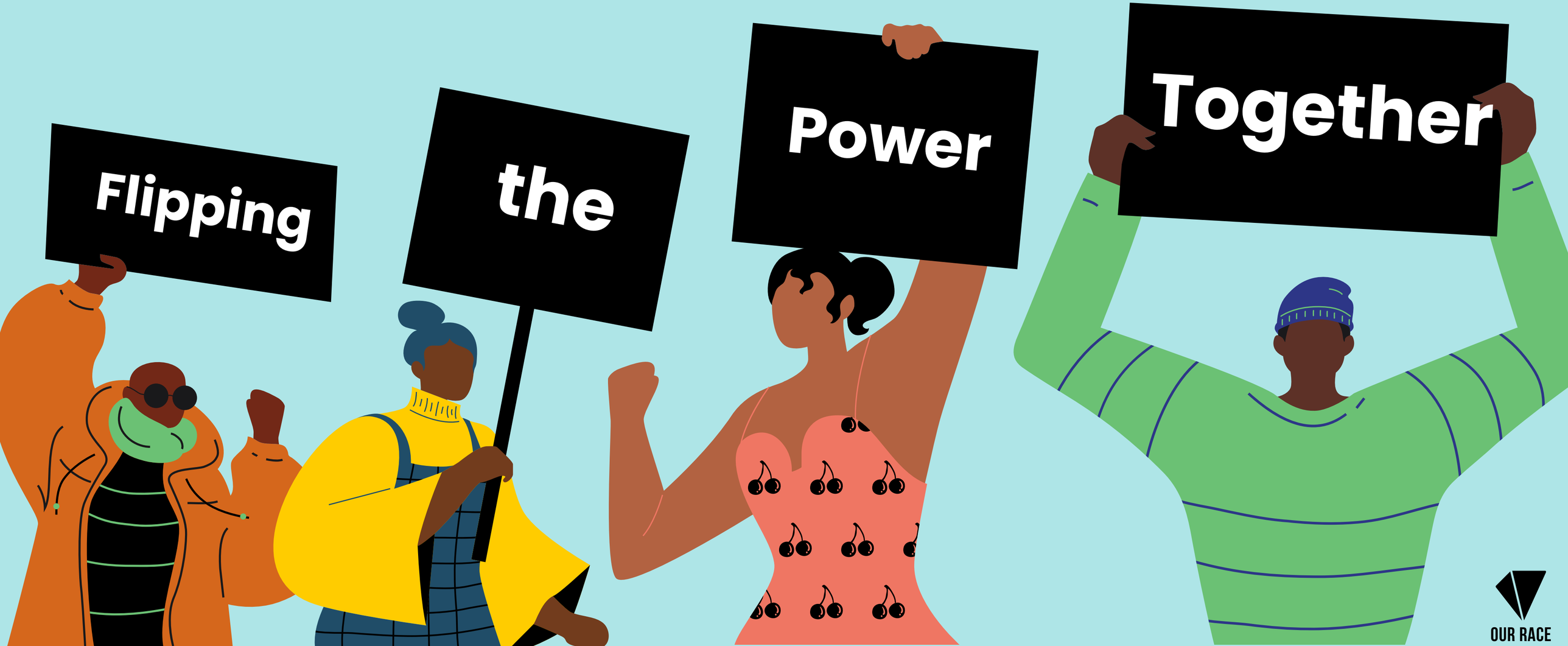
Storytelling and Addressing Racism in Healthcare



OUR RACE

Language Matters

"I always think about the data as a story, and each person as a storyteller. . . What is our responsibility to the story and to the storyteller?"

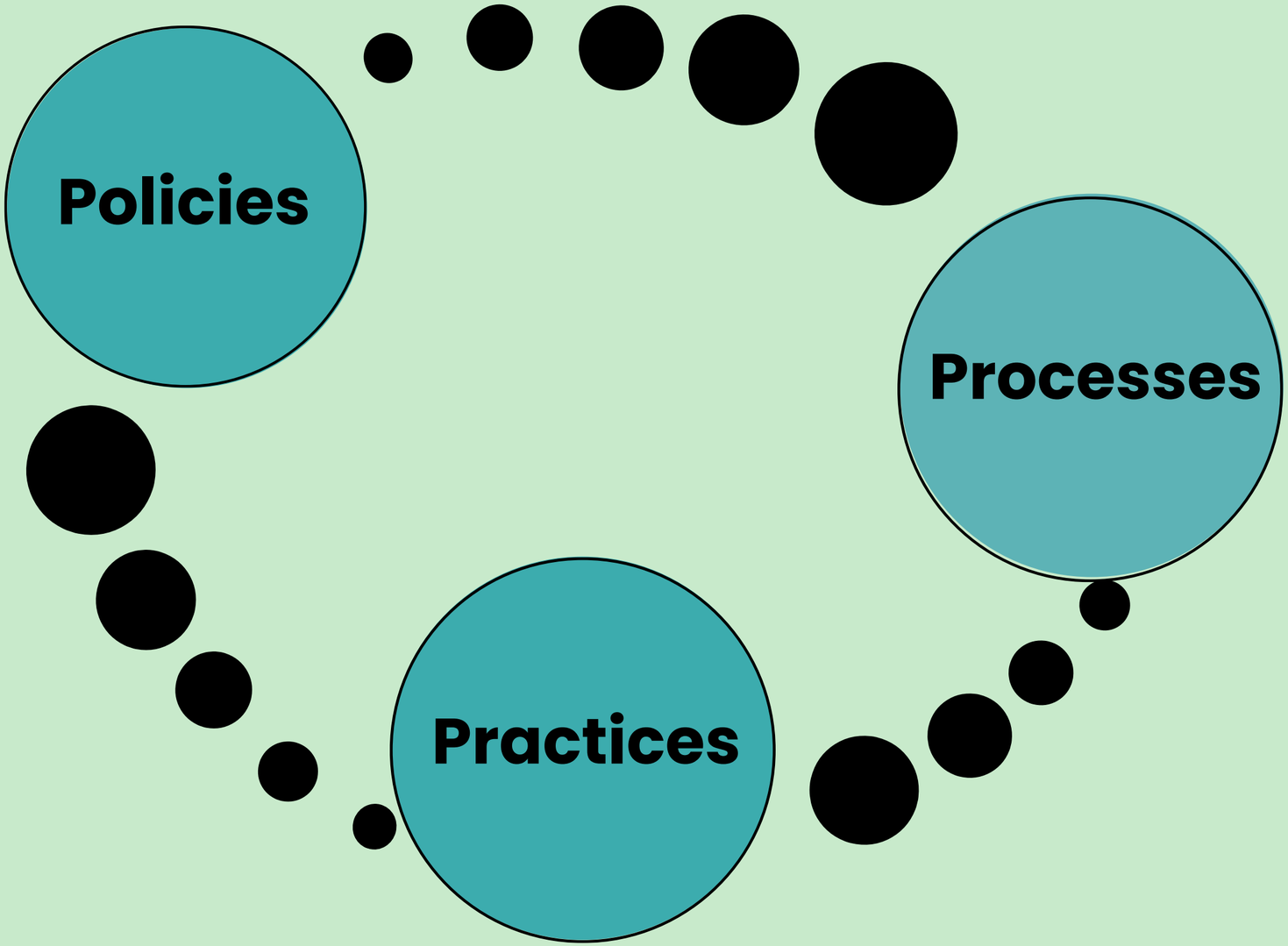
Abigail Echo-Hawk (Pawnee)

Chief Research Officer for the Seattle Indian Health Board

Indigenous Concepts of Data

OUR RACE

Aligning the 3Ps



OUR RACE

What is T.E.S.T.?

- do no harm
- cultural humility
- centre lived experience
- continual journey
- measure success

T.E.S.T. is an anti-oppressive framework which aims to flip the Story Telling balance of power, where each person's rights and needs - regardless of their race, ethnicity, language, age, gender, religion, sexual orientation, gender identity, gender expression, health, ability, economic status or background -must be respected.

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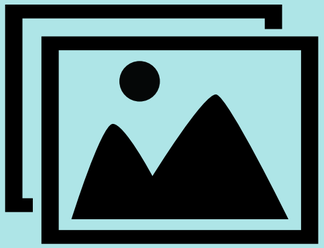
What is a Story?

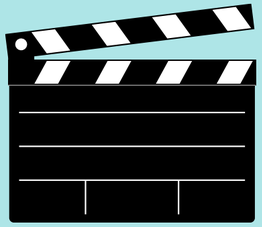
Idea/Inventions



Image/Photo/Portrait

Tweet

Action



Film/ movie/ video

Audio/Interview

Article/Novel

Lived experience

Everywhere we look we can find a Story.

OUR RACE

What is copyright?

Who owns copyright?

- ***Generally the "author" of the material***

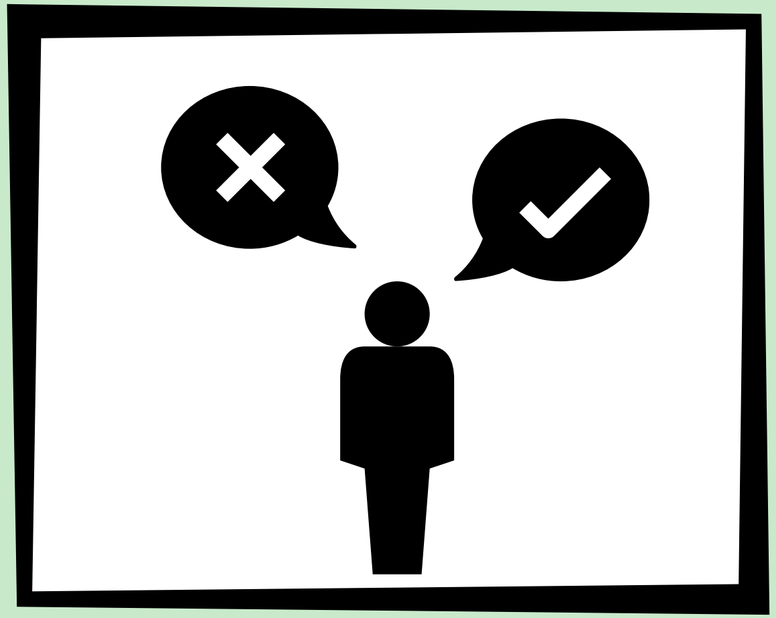
When does copyright protection arise?

- ***Material form***
- ***Original***

OUR RACE

Who is a Story Holder?

- **Everyone can be a Story Holder.**
- **A Story Holder is a person with the lived experience- the custodian/owner of their Story.**
- **The Story Holder may choose to share the Story or not.**



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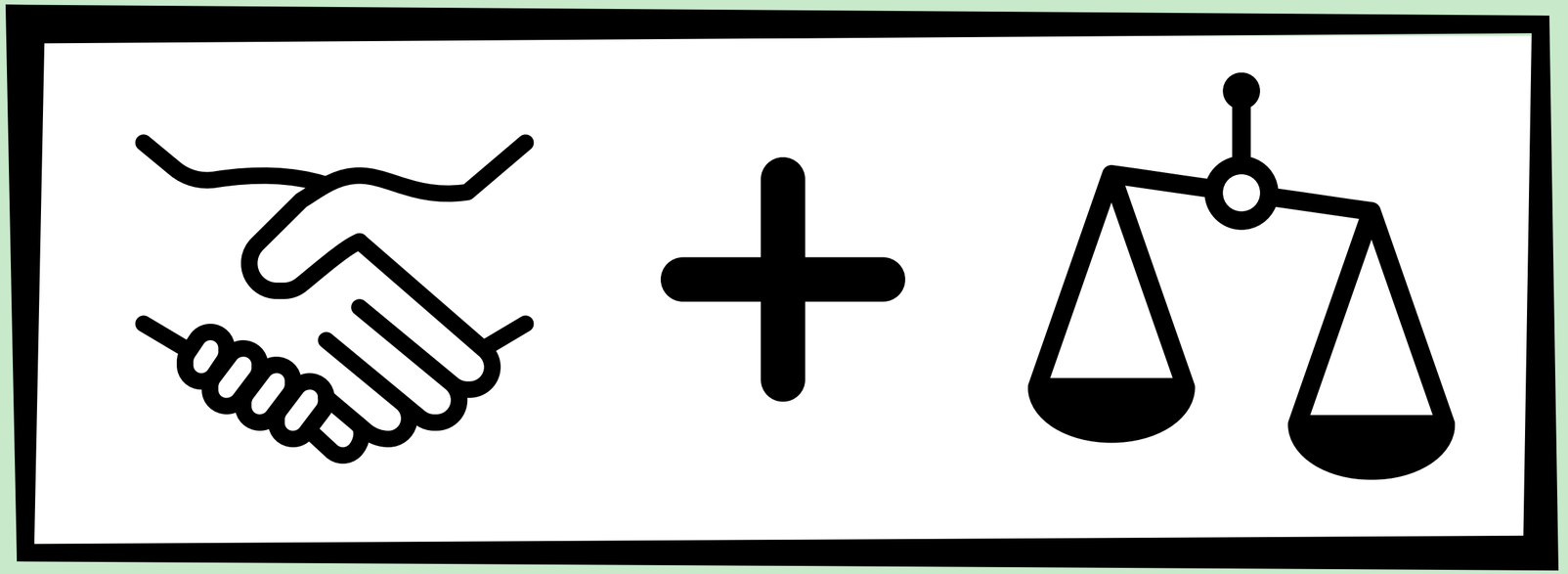
Who is a Story Caretaker?

A Story Caretaker is a person or organisation who engages a Story Holder to share their Story and commits to the Transformational Ethical Story Telling Principles.



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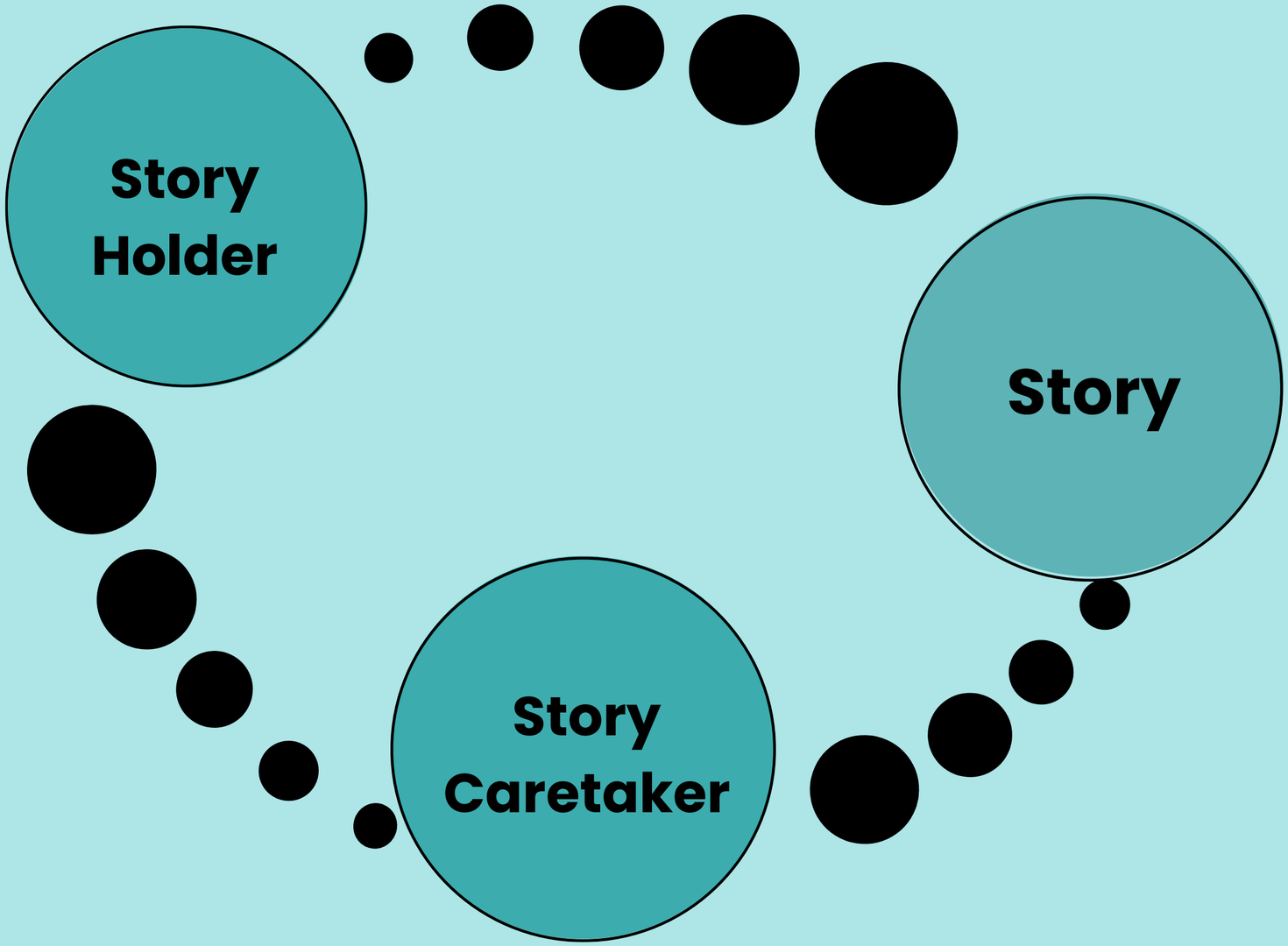
T.E.S.T. Space



OUR RACE

Directed by and/or told by those with more power

Obligation placed on the Story Holder - imposed identification

Emotional burden and trauma

Time takes precedence over the potential impacts of the Story

Transactional consent practices

Stereotyping, dehumanising and cultural appropriation

Not providing a safe space

The Story is edited without the Story Holder's input

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Projects

Case Management

Field research

Reports and evaluations

Events

Communications and marketing

Awareness days

Training

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T.E.S.T. Principles

1. Free, prior and ongoing informed consent

2. Resourcing and Sensitivity

3. Empowerment

4. Co-design and Collaboration

5. Integrity of Story

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What is standard consent practice?

THIS DEED WITNESSES AS FOLLOWS:

1. The Participant grants XTRACTR and its agents and assigns, the **irrevocable, exclusive, royalty free and unconditional right** to use, publish, display, distribute or alter the Content, for any purpose, including, but not limited to, for commercial use or the advertising, promotion or publicity of XTRACTR and its products and services, in any media, now or hereafter known, worldwide, in perpetuity, without remuneration.

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Source: https://www.insider.com/abortion-billboard-model-non-consent-girl-african-american-campaign-controversy-2022-06

T.E.S.T. Principles

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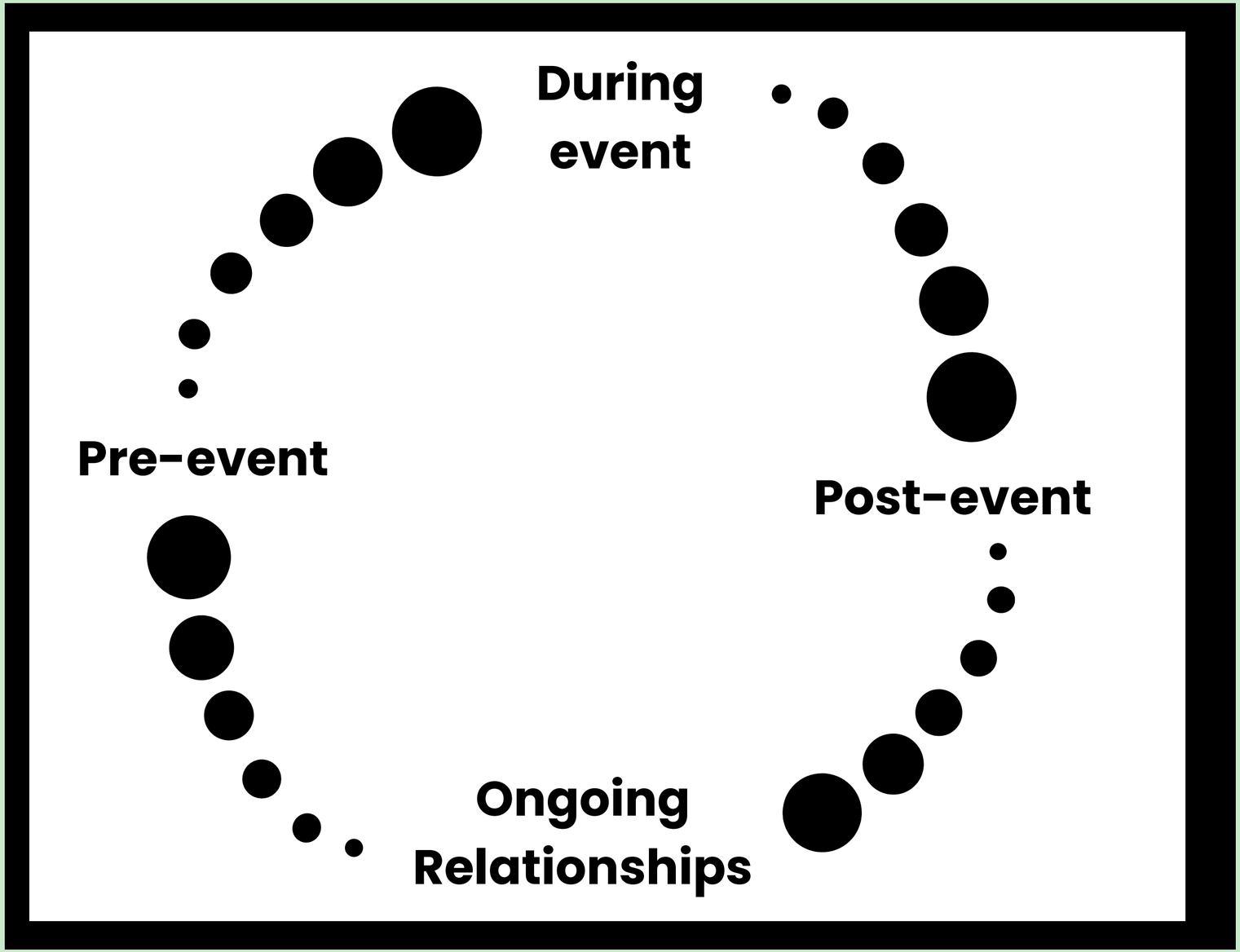

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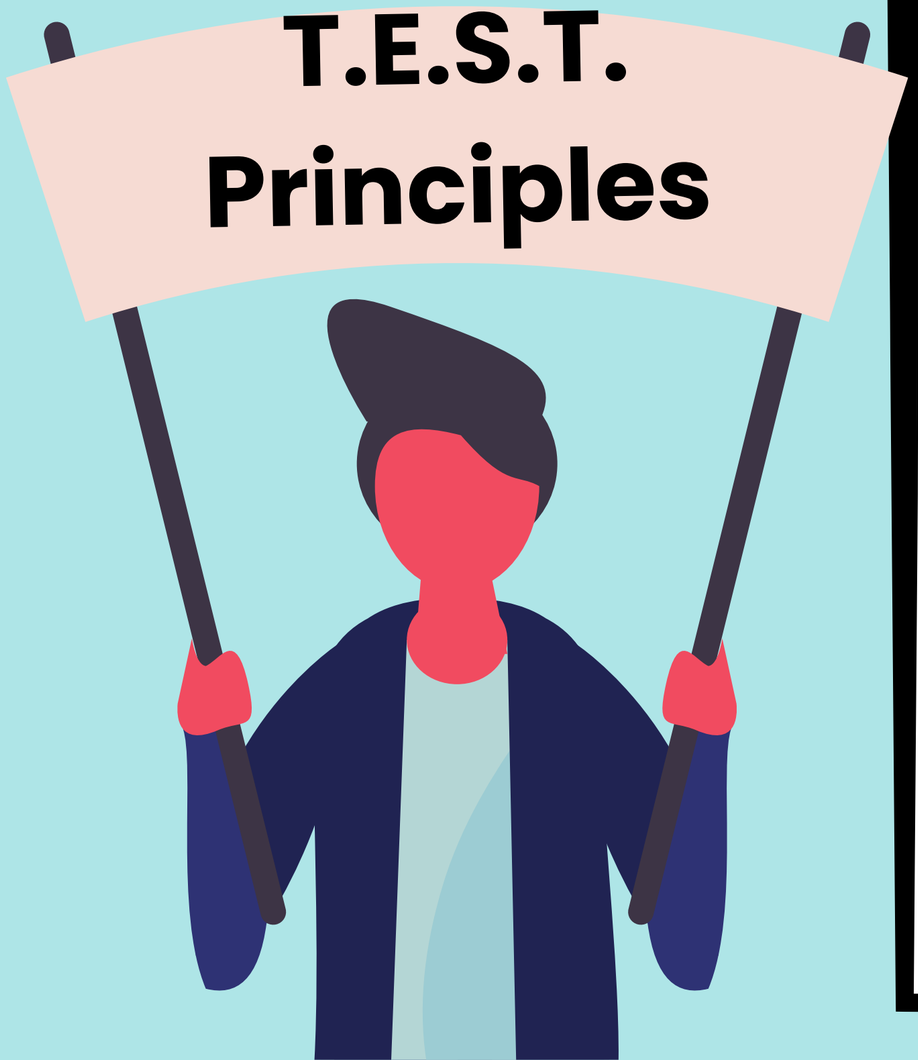
T.E.S.T. Principles



1. Free, prior and ongoing informed consent

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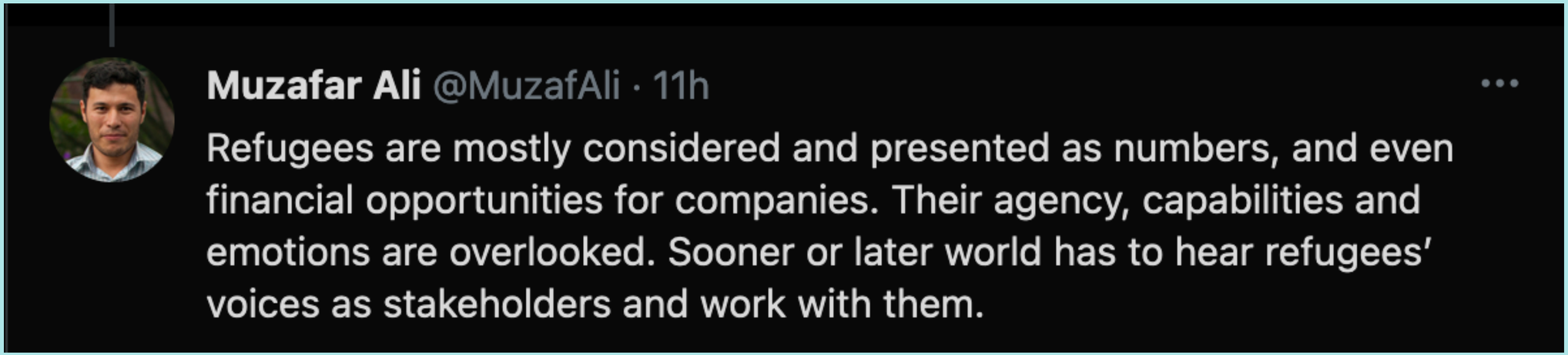
Architects, not Objects



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T.E.S.T. Principles

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SAMMEN

Challenging the Deficit Story

Ethical Story Mapping and Audit

TRANSFORMATIONAL ETHICAL STORY TELLING (T.E.S.T.) STRATEGY REPORT

On the implementation of the Our Race Transformational Ethical Story Telling principles at Médecins Sans Frontières Australia

November 2023

MEDECINS SANS FRONTIERES
DOCTORS WITHOUT BORDERS

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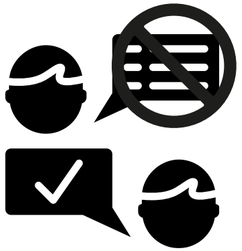
SCHEDULE 1: T.E.S.T. CERTIFICATION AND ACTIVITY CHECKLIST

This checklist includes key criteria to become T.E.S.T. Certified and to continue to embed the T.E.S.T. principles on an ongoing basis. This checklist will allow for MSFA to become T.E.S.T. Certified while also providing key activities which further enhance ethical storytelling policies, processes and practices.

For MSFA to receive certification the highlighted items must be completed.

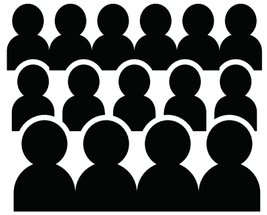
Who directs and sets the terms of engagements for the project/Story?

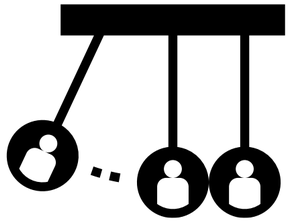
Who is benefiting from the Story being told?



Whose voice is included and whose voice is excluded?

Who is the main audience of the Story?





How are the Story Holder and their communities impacted?

T.E.S.T. Principles

1. Free, prior and ongoing informed consent

2. Resourcing and Sensitivity

3. Empowerment

4. Co-design and Collaboration

5. Integrity of Story

OUR RACE

Editing = Erasure

"This is the first time in my life that I understood the definition of racism....Does that mean I have no value as an African Activist or the people from Africa have nobody at all"- Vanessa Nakate

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Who owns the Story?
Organisation owns copyright and IP

How are Story Holders involved in the editing process?

Who has access to and control of Stories?

Where and for how long are Stories stored?

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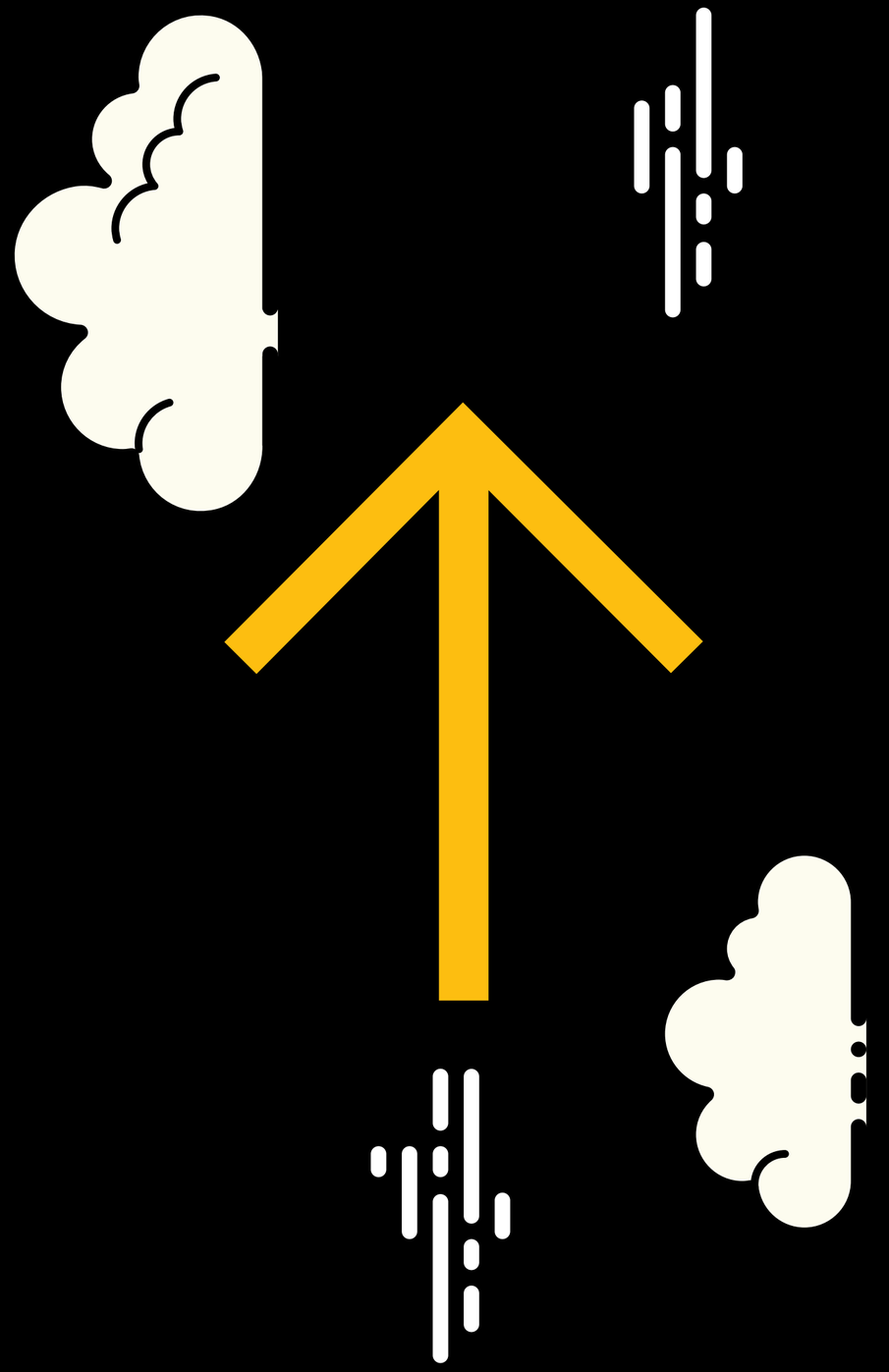

Where Next?

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1. Story Caretaker Workshops
2. Story Holder Workshops
3. Collaborative Consulting & Legal Support
4. Implementing T.E.S.T.
5. T.E.S.T. Certification

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FLIP THE POWER

> No matter what our intentions, everything we say and do in the pursuit of justice will one day be outdated, ineffective, and yes, probably wrong. That is the way progress works. What we do now is important and helpful so long as what we do now is what is needed now.
>
> — Ijeoma Oluo

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