

Data commons and chronic health NeLL 27.11.20

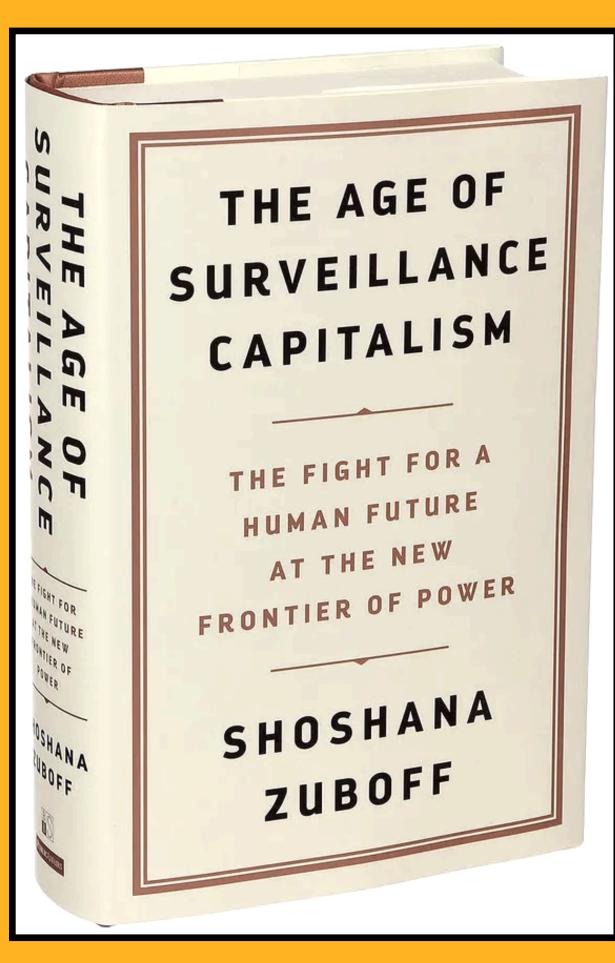
Marleen Stikker

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The internet is broken ...





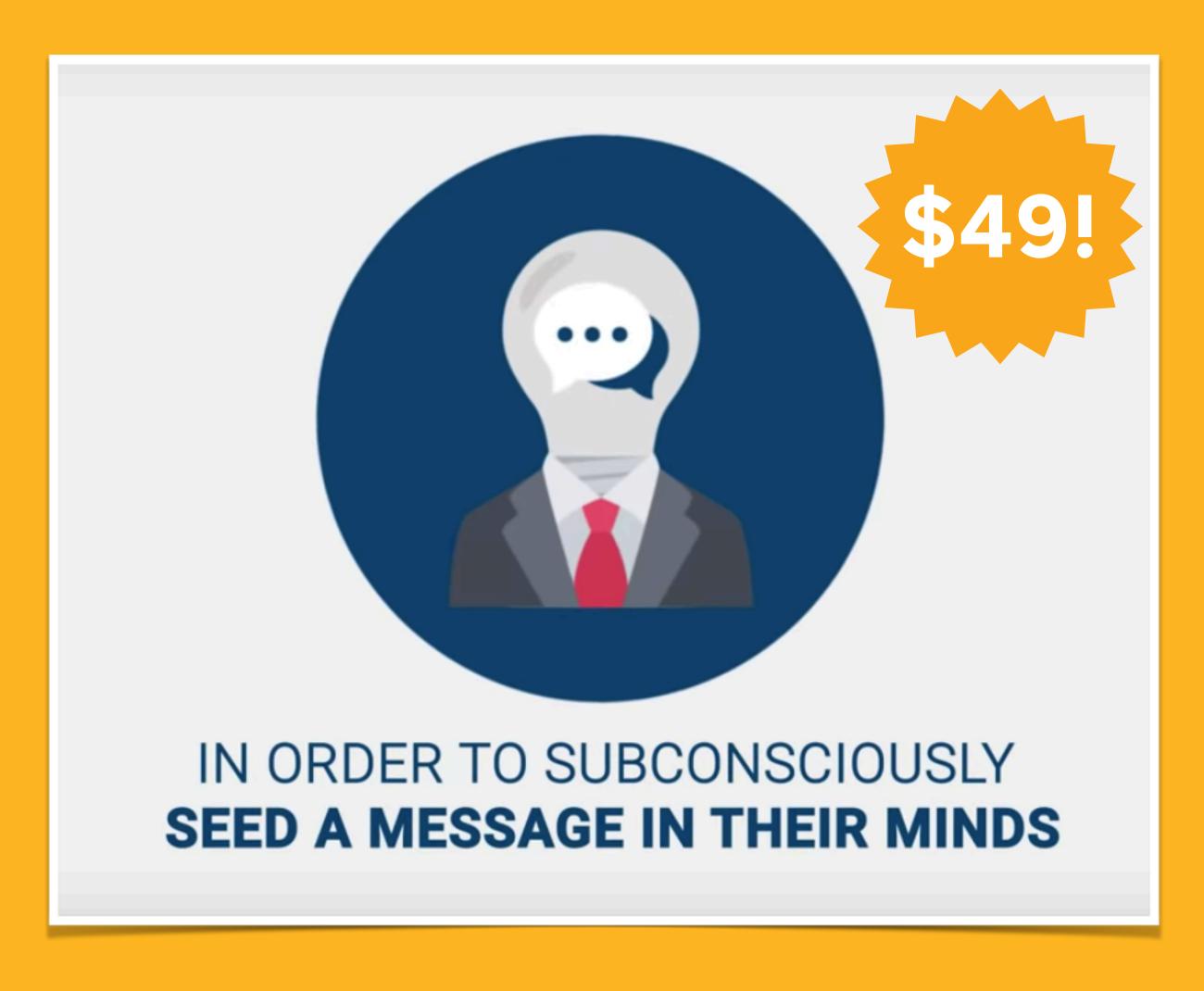








It's the businessmodel, stupid



THE SPINNER

Get your partner to...

... propose marriage!

... try polyamory!

... get a breast augmentation!

... quit gaming!

... quit smoking pot!

... accept your gaming habit!

... accept your pot smoking habit

"The most potent weapon in the hands of the oppressor is the mind of the oppressed."

- Steve Biko

... but we can fix it

1. Change the Narrative demystification | societal intelligence



2. Rule of Law Break up big tech

3. Reclaim Economics
Commons not markets
at the centre

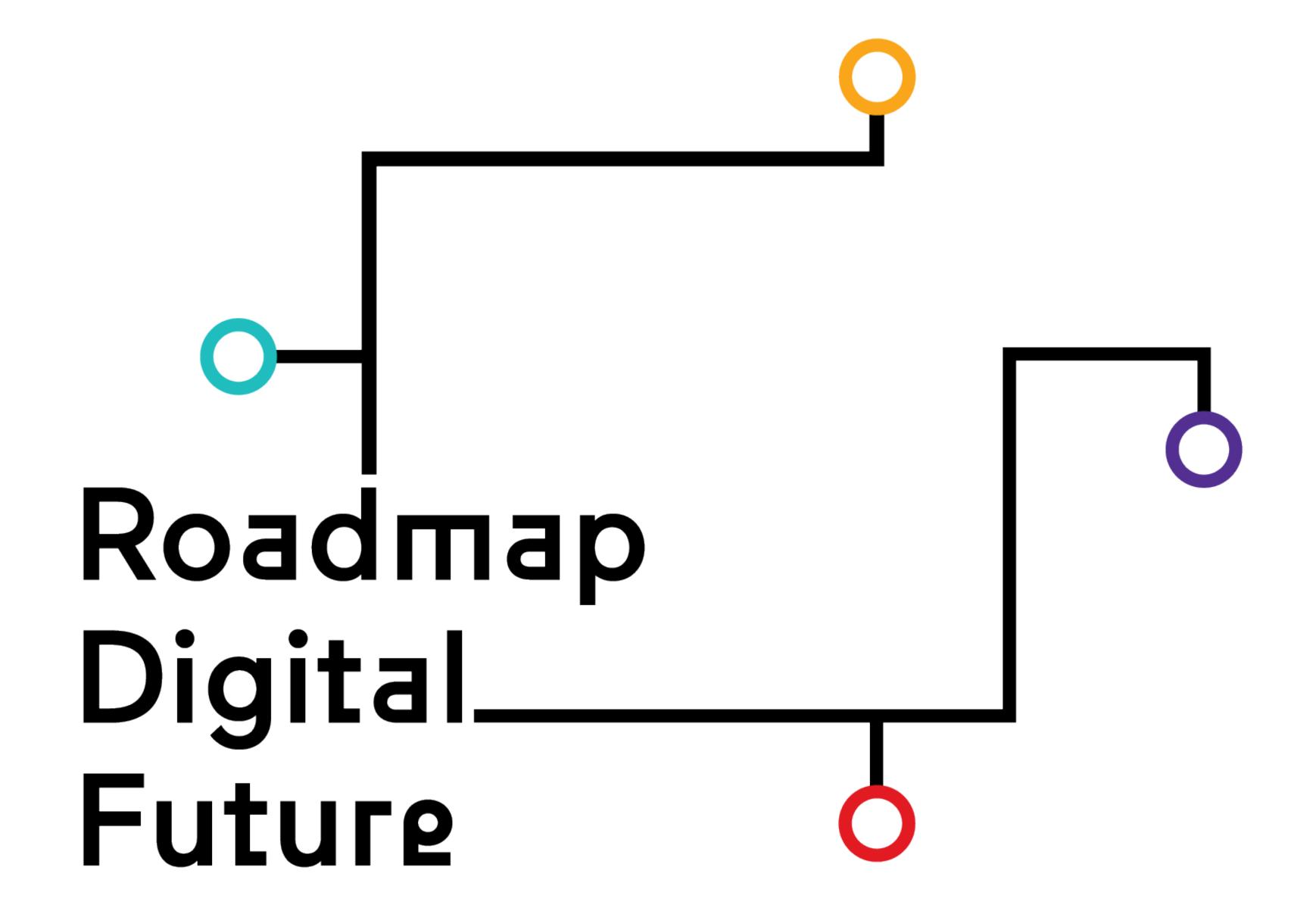
4. Transformative Innovation

Interdisciplinary and inclusive design

5. Open Digital Public Spaces

Internet as a commons

technology is not neutral



applications closed - black box big tech in control - extraction of value surveillance capitalism human values and democracy at stake valu

Where we are

applications
In the future

- open / public
- society in control
- regenerative
- data minimalisation
- fair and sustainable

valu

Where we want

to go

How to keep critical and essential technologies open?



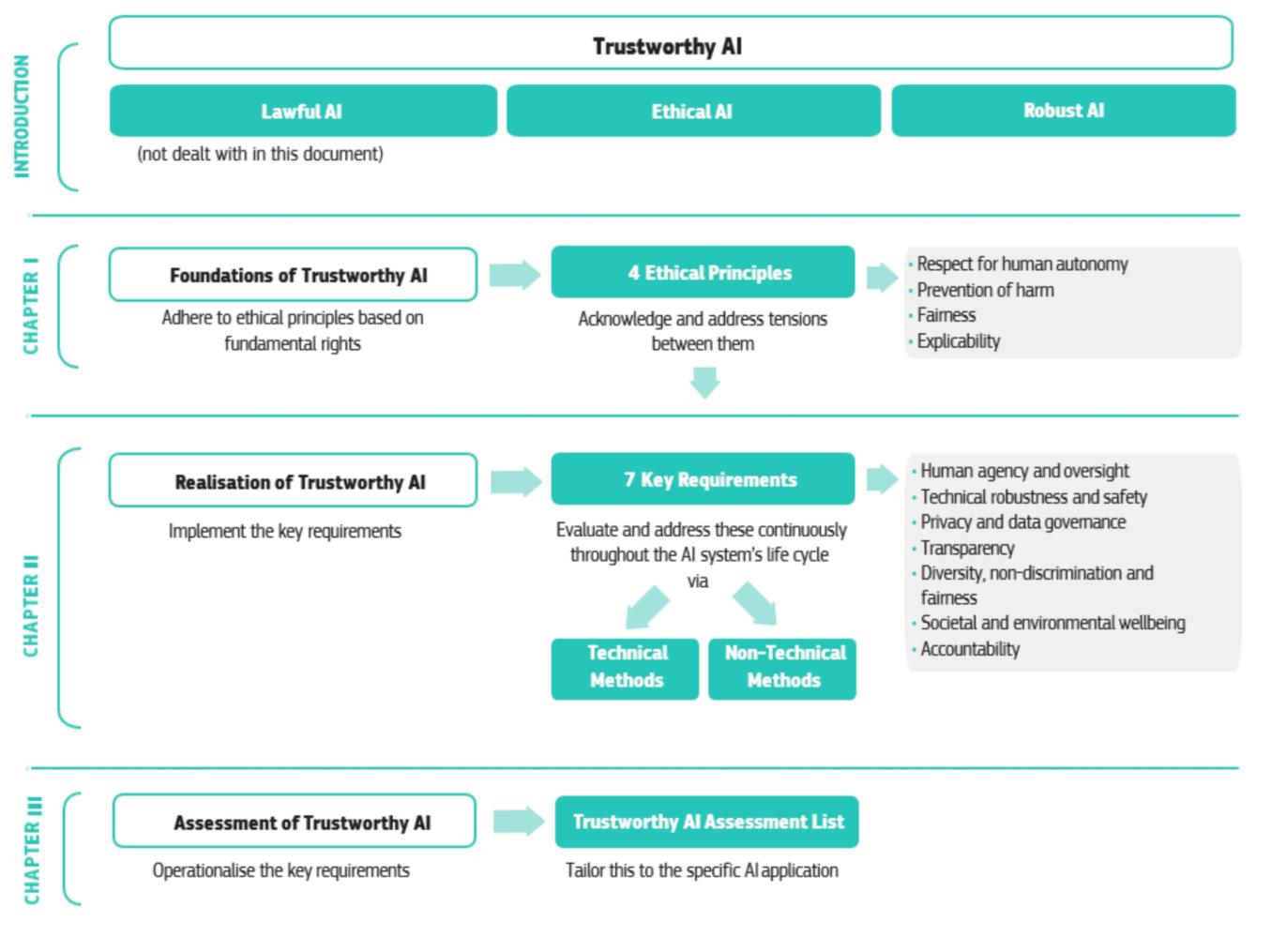
Open Surgery (2016)

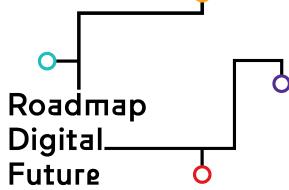
Frank Kolkman

Frank Kolkman investigates whether DIY surgical tools could be an accessible alternatives to the costly medical health services worldwide. Inspired by the discovery of a slew of YouTube video's in which uninsured Americans can be seen performing basic operations for others to imitate, the project extrapolates on this phenomenon by proposing a DIY robot assisted surgery system for domestic keyhole surgery.



Who owns the Al?





https://ec.europa.eu/digital-single-market/en/news/ethics-guidelines-trustworthy-ai

Beware of Ethics-washing

Definition by Thomas Metzinger:

Organising and cultivating ethical debates in order to

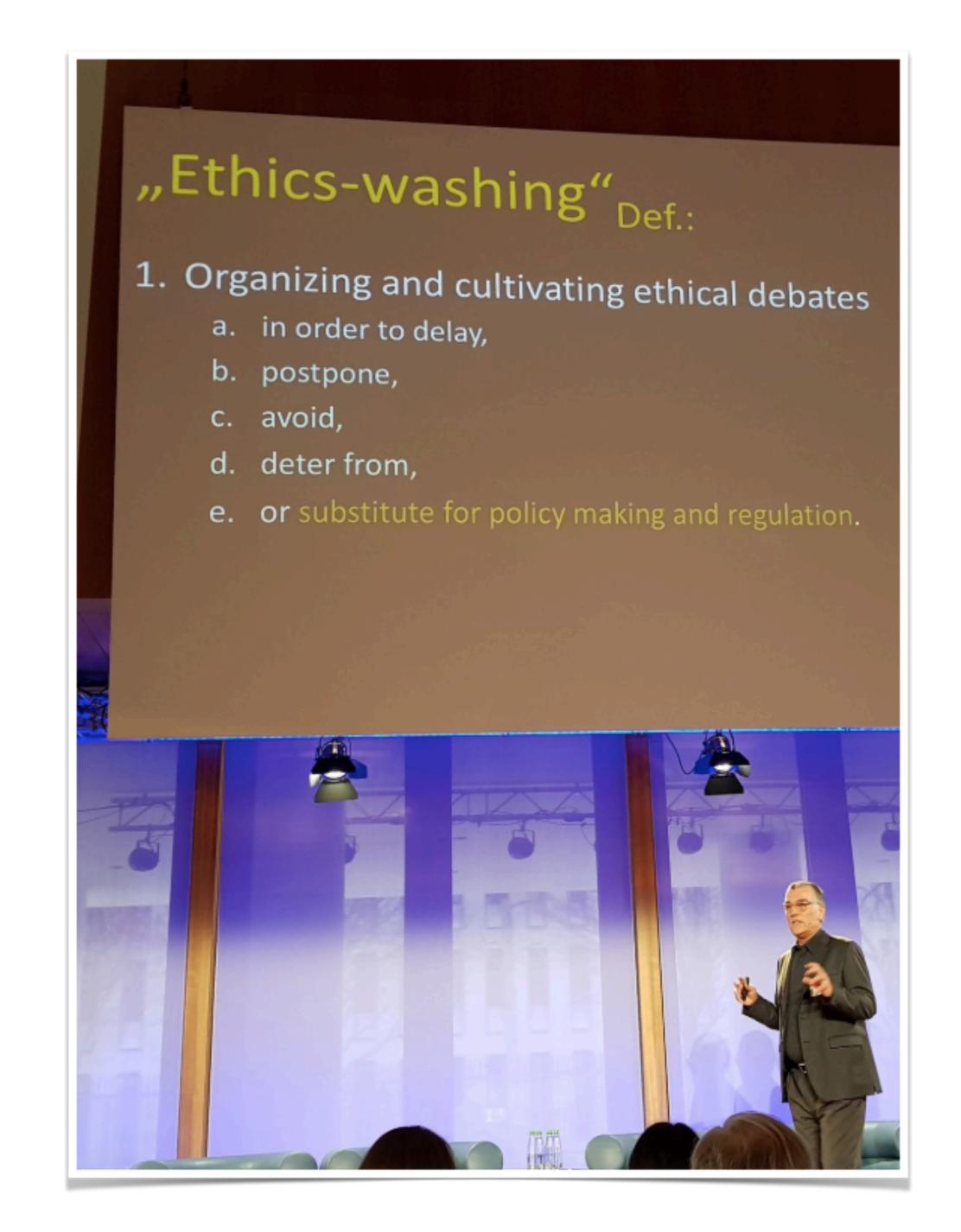
a. delay,

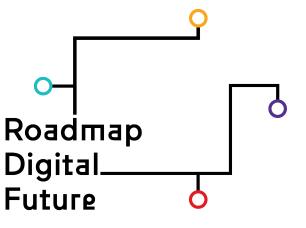
b. postpone,

c. avoid,

d. deter from,

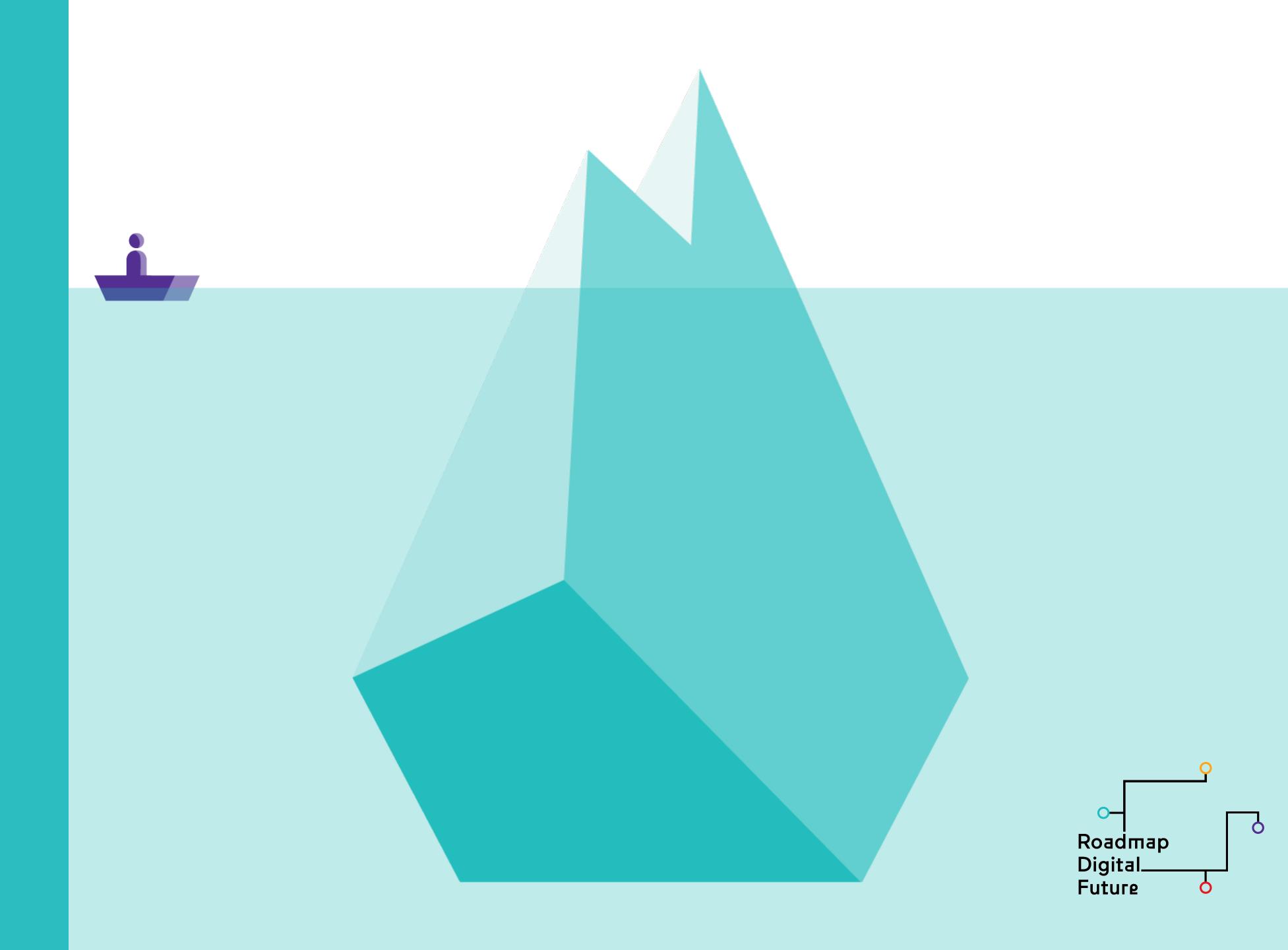
e. or substitute for policy making and regulation.



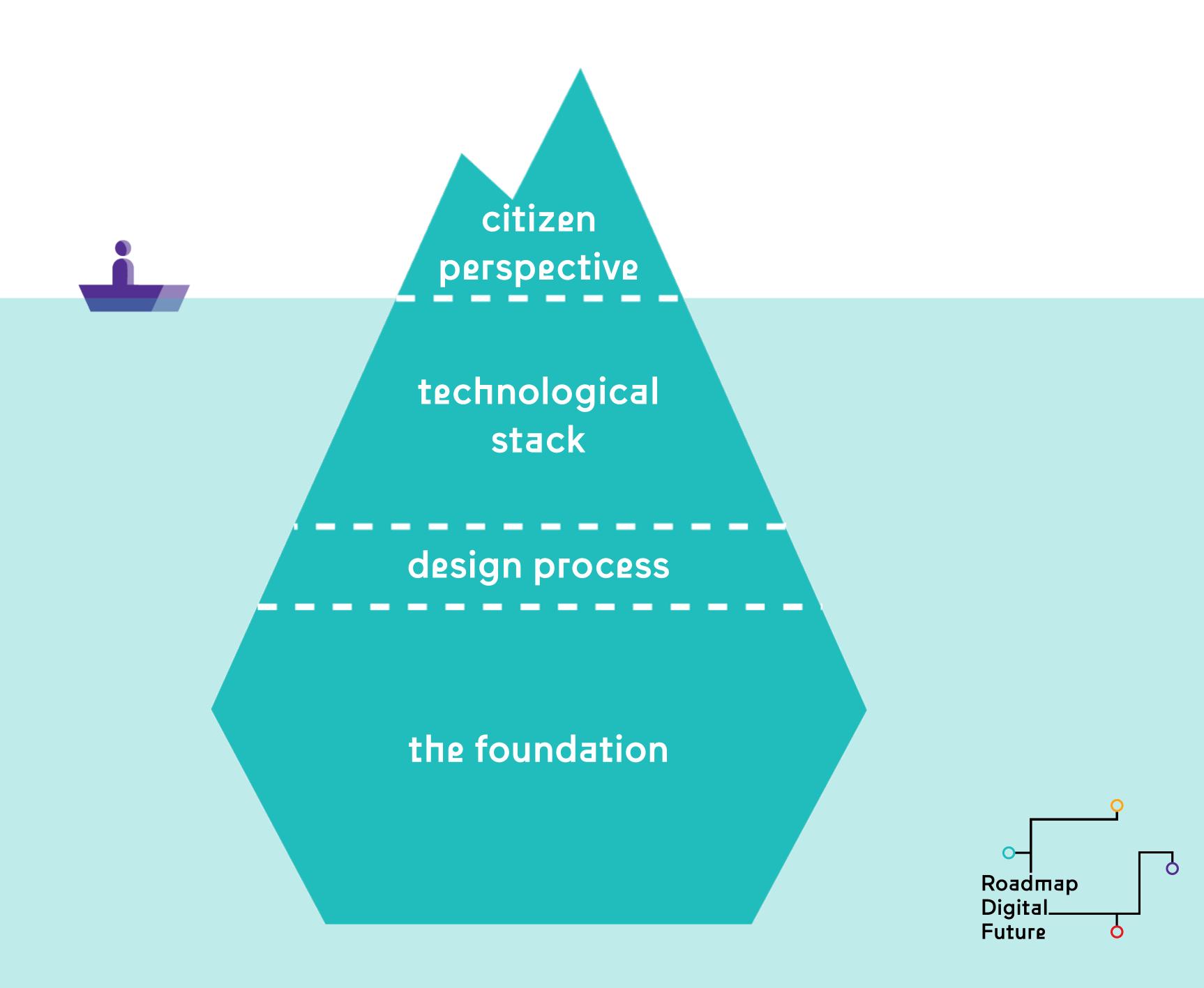




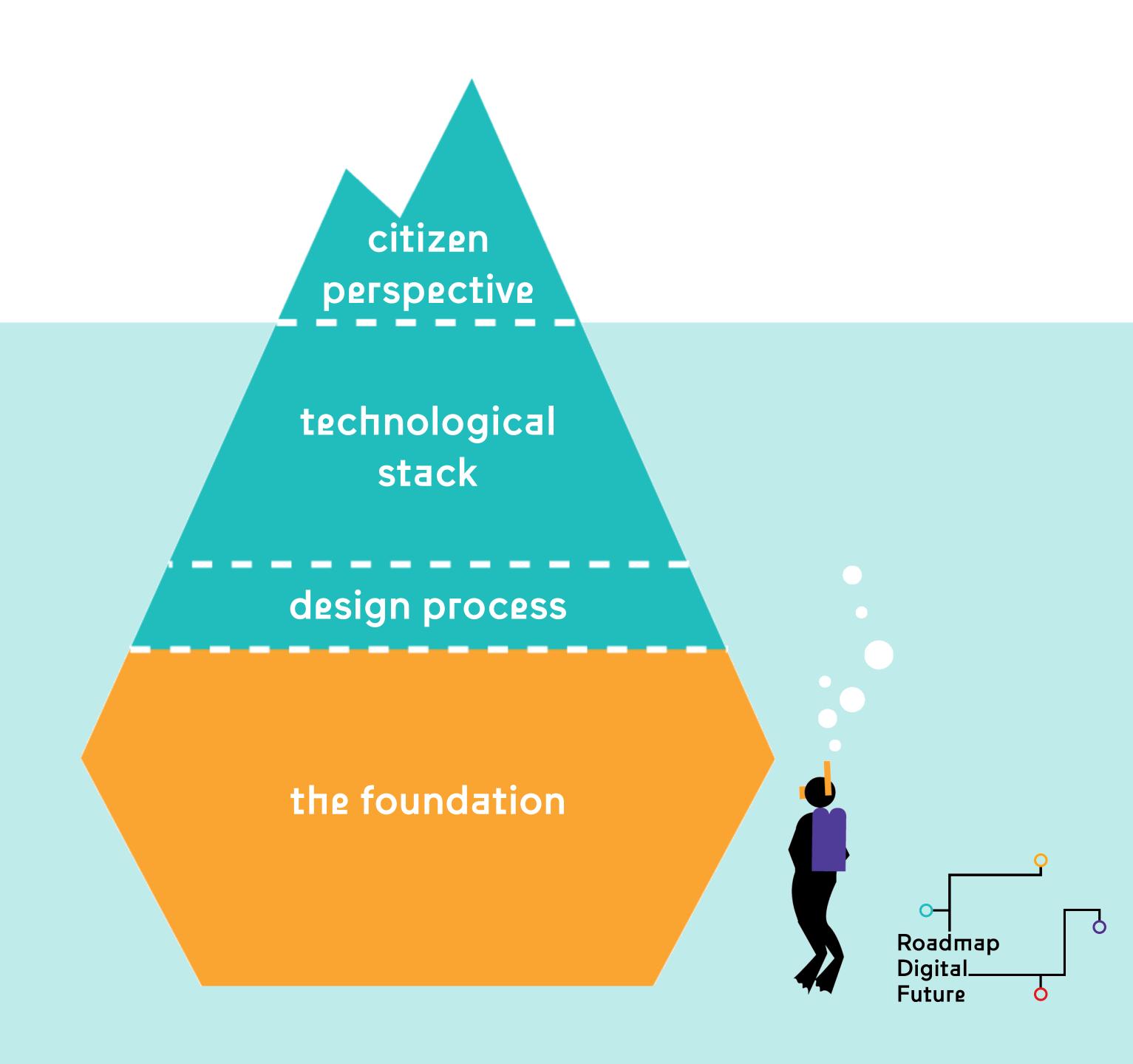
most of technology is invisible



more than technology



can we make sure
that the
technology stack is
inclusive, safe and
just





1. starting points and assumptions

acknowledge that humans are bias

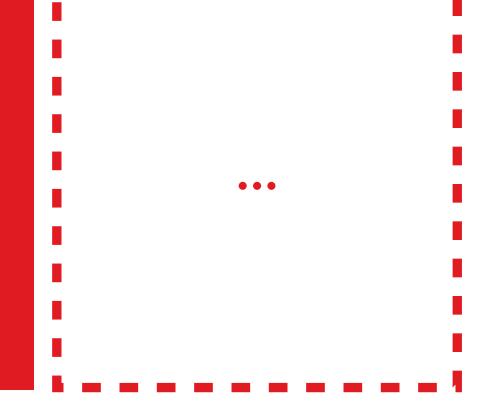
by default

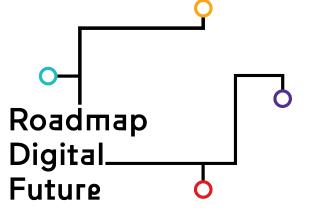
and so is technology

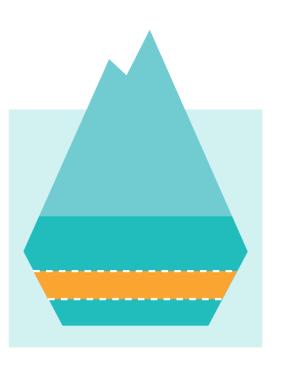
What is your worldview?
Your privilege?

Who defines the problem? Who defines success?

Where are we optimising for?







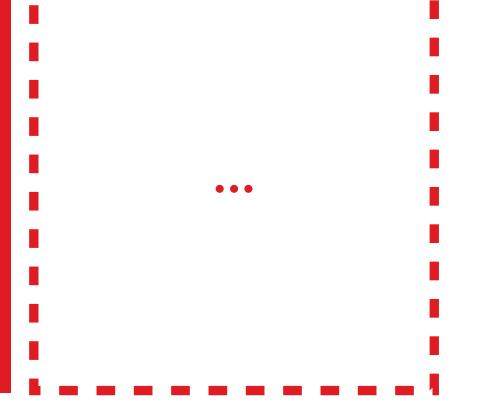
2. fundamental rights and values

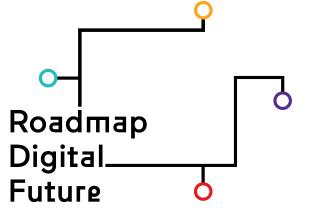
human rights
guaranteed and
public values
respected

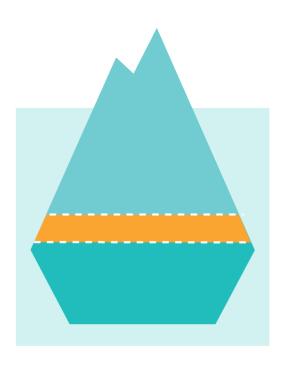
How does the initiative safeguard fundamental rights?

In what way is society represented?

How do shared public values resonate in this initiative?







3. socio-economic considerations

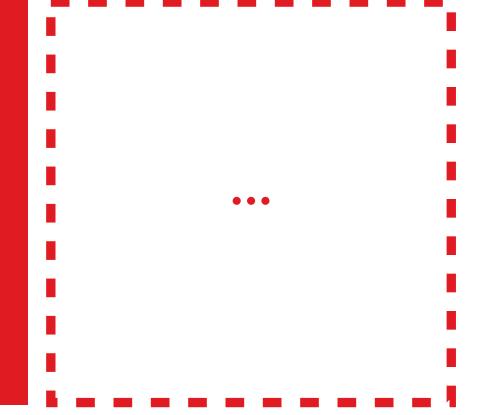
financial-economic model regenerative

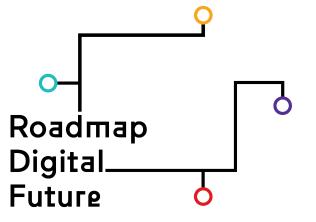
non-extractive

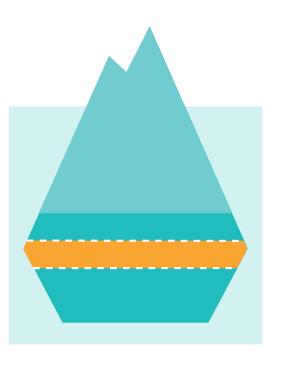
What is the financing model? Who owns?

How are risk and profit shared in society?

What is the environmental impact of the intended technology?







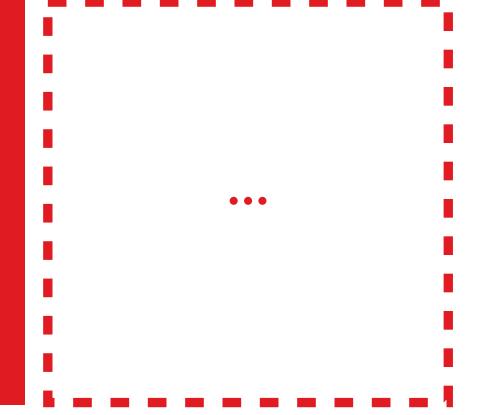
4. governance and supervision

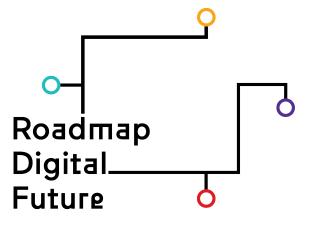
society in control

How is governance organised?

Who is accountable for this initiative, and to whom?

How is supervision involved after completion of the initiative?



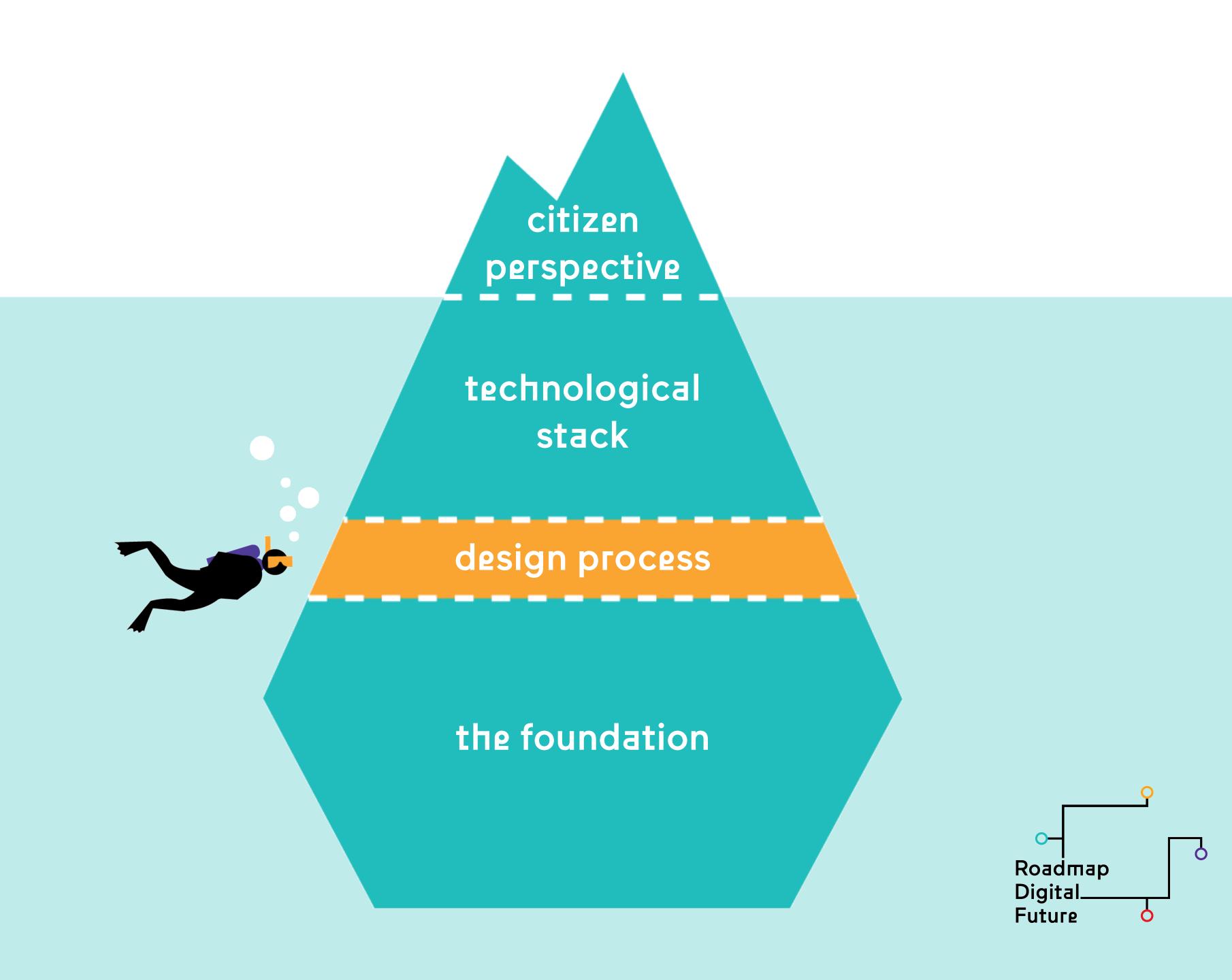


ethics are in the design process

who can participate?

who defines the challenge?

who owns the outcomes?



Key Enabling Methodologies

- 1. Vision and imagination
- 2. Participation and cocreation
- 3. Behaviour and empowerment
- 4. Experimental environments
- 5. Value creation and scaling
- 6. Institutional change
- 7. Systemic change
- 8. Monitoring

TECHNOLOGIE (KET's)

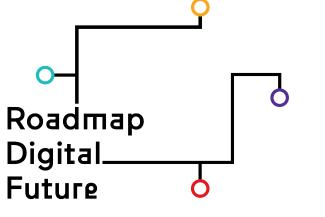
ontwikkeling van technologie op basis van veronderstelde mogelijkheden

SLEUTEL-METHODOLOGIEËN (KEM'S)

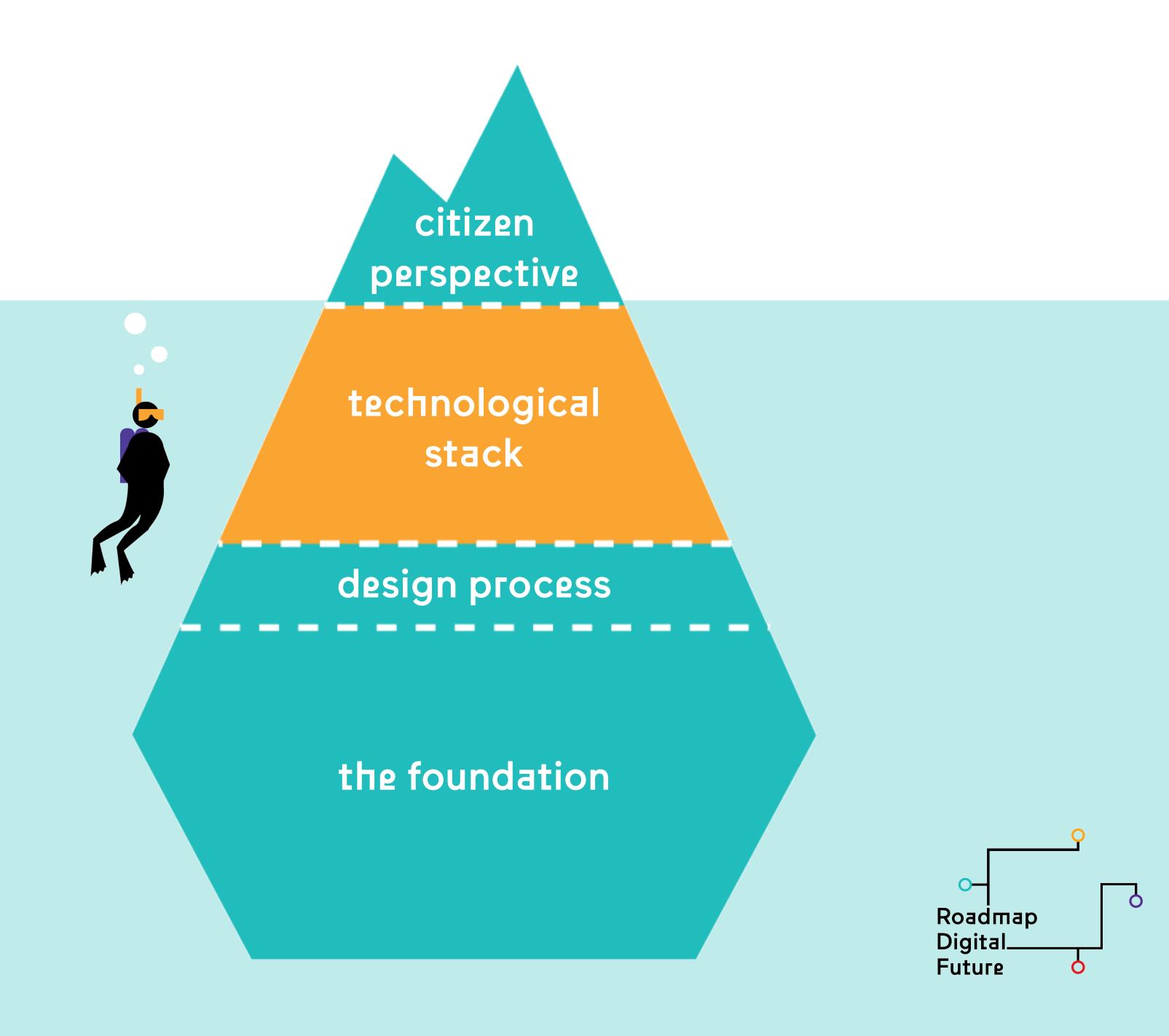
verbinden door middel van interventies / innovaties met behulp van methoden, strategieën, tools, processen, etc.

MENS/ **MAATSCHAPPIJ**

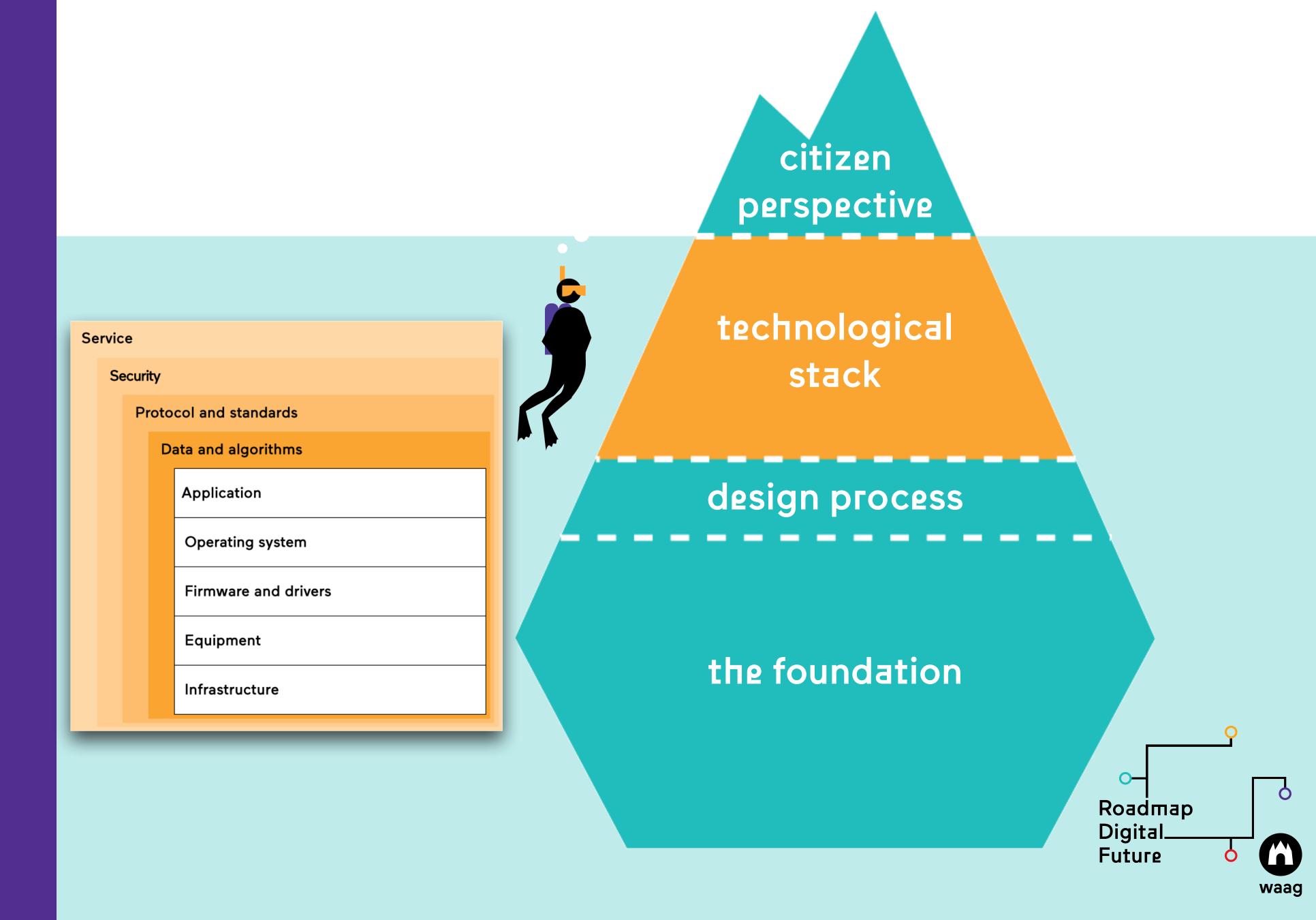
kennis over mens en samenleving: onder andere gedrag, ethiek, beleid

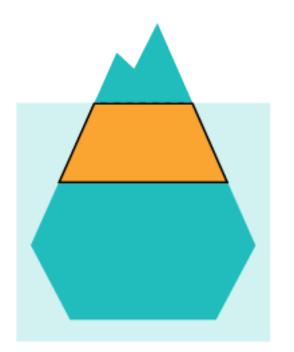


the tech stack



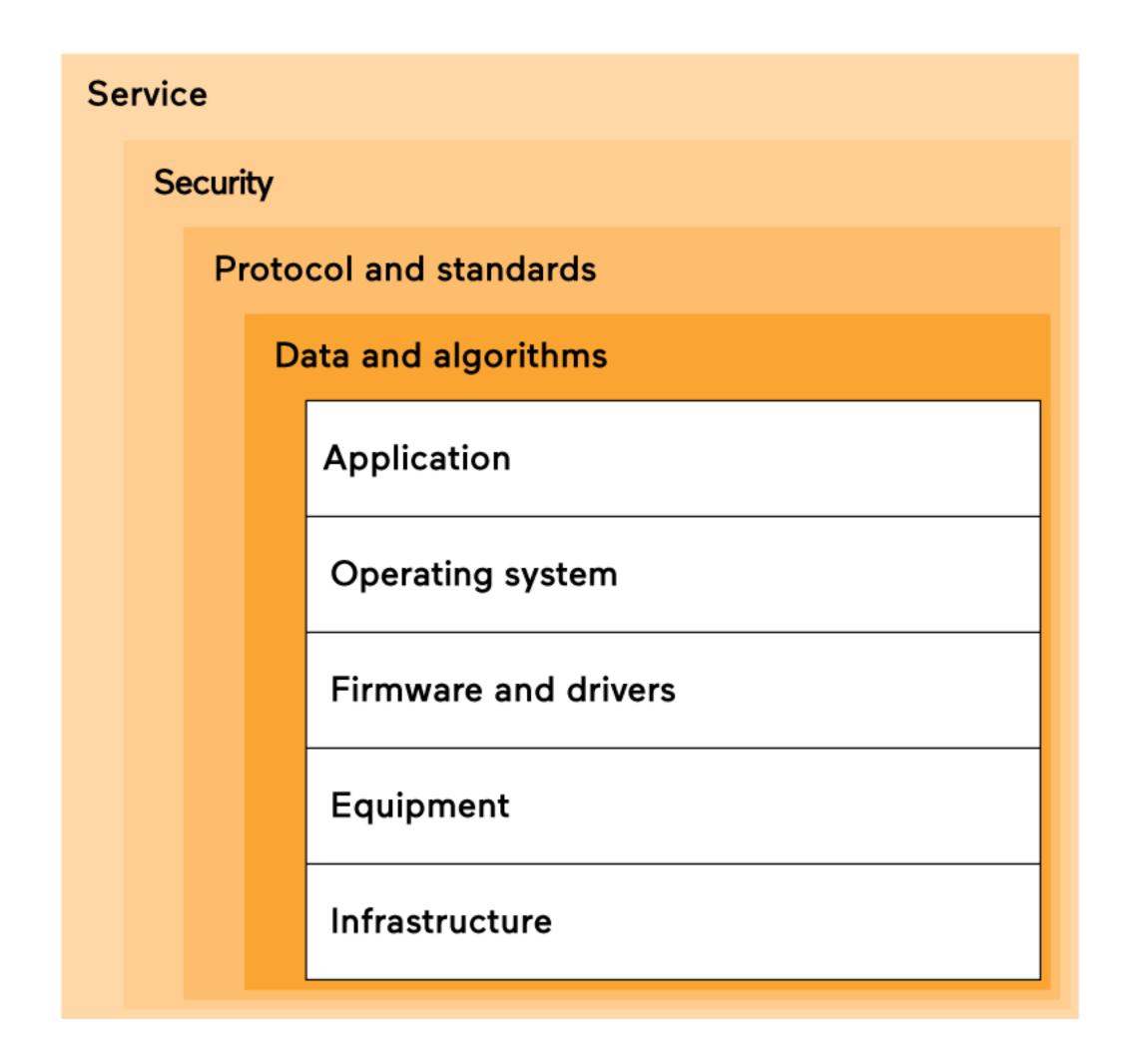
open the black box

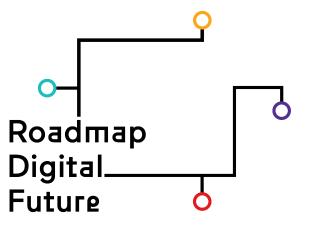


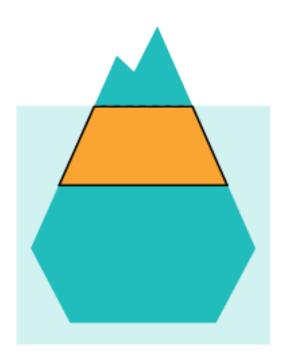


technological stack

How can we codesign the technology we rely on?

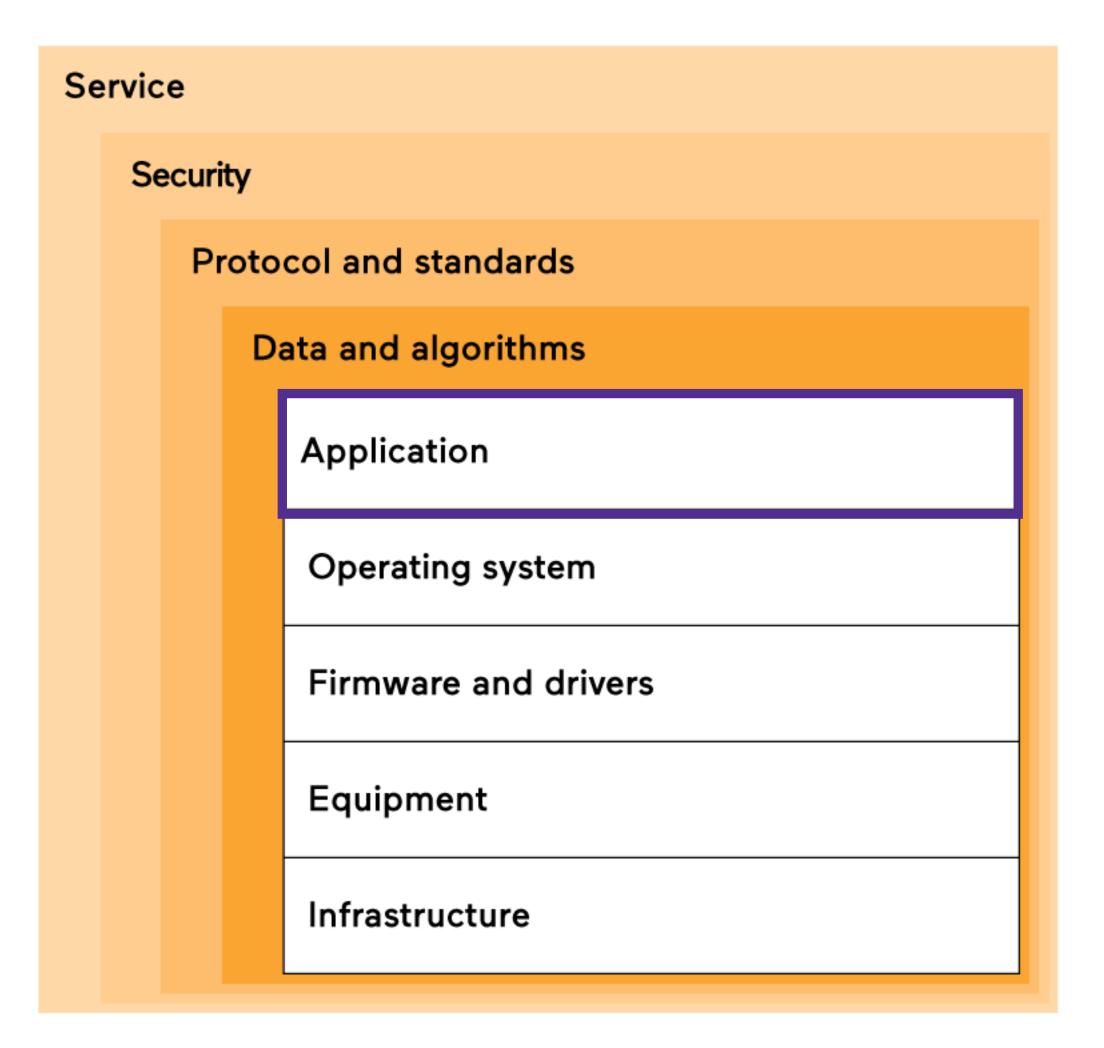


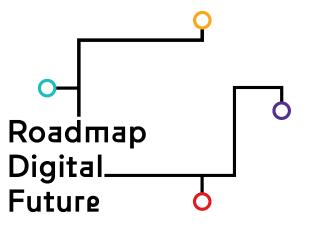


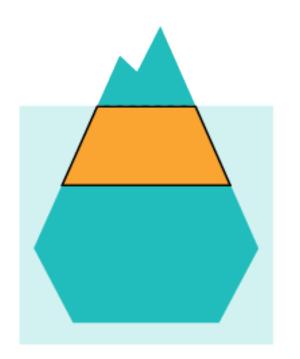


technological stack application

"Applications that are open source can be checked and built on by anyone"

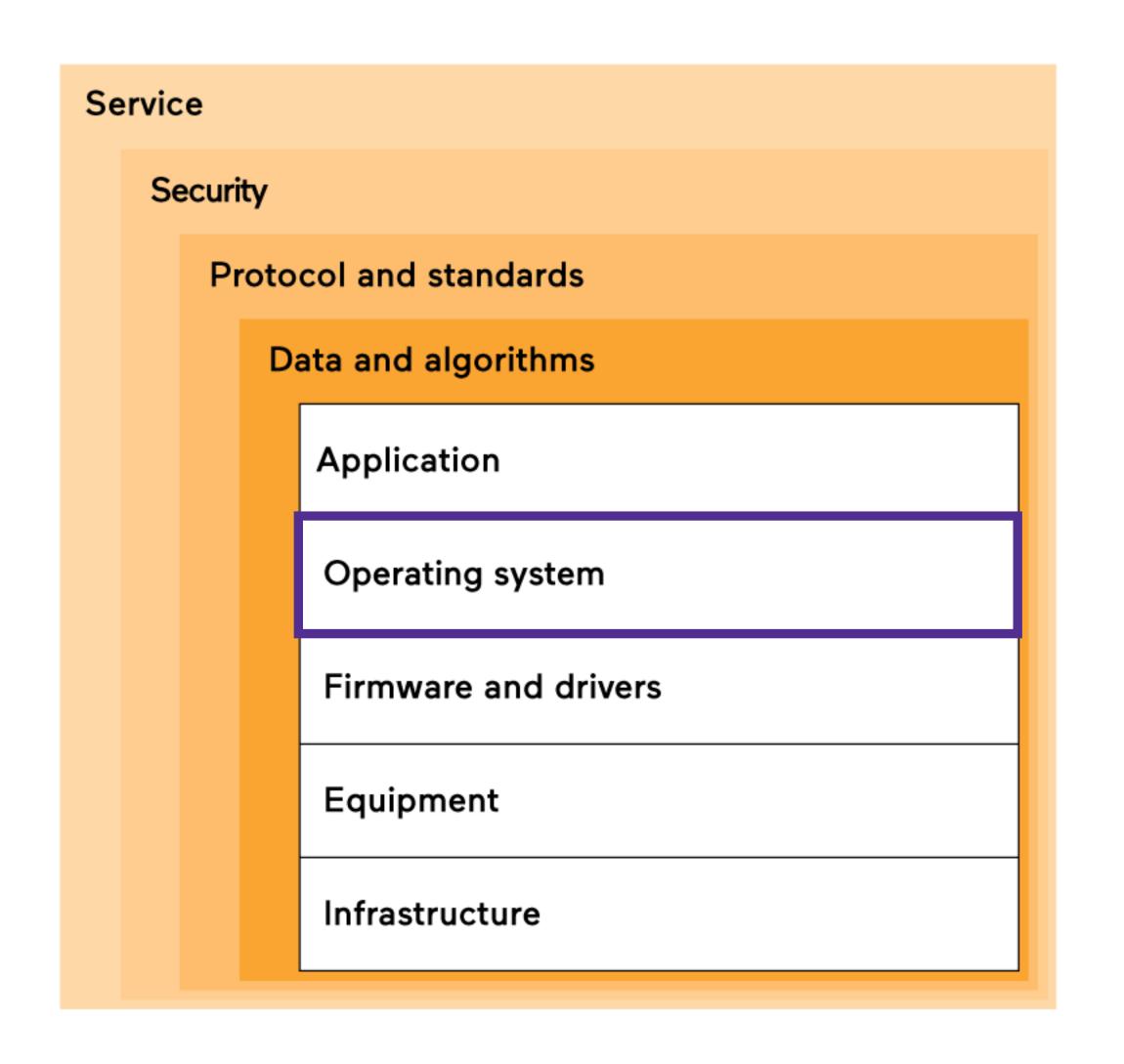


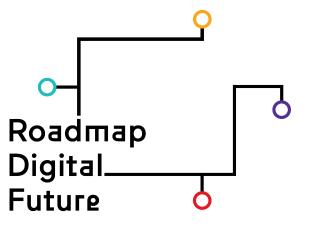


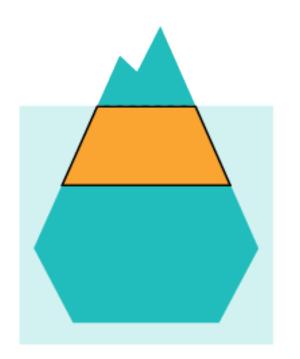


technological stack operating system

"People should be able to control and adapt the operating systems on their devices"

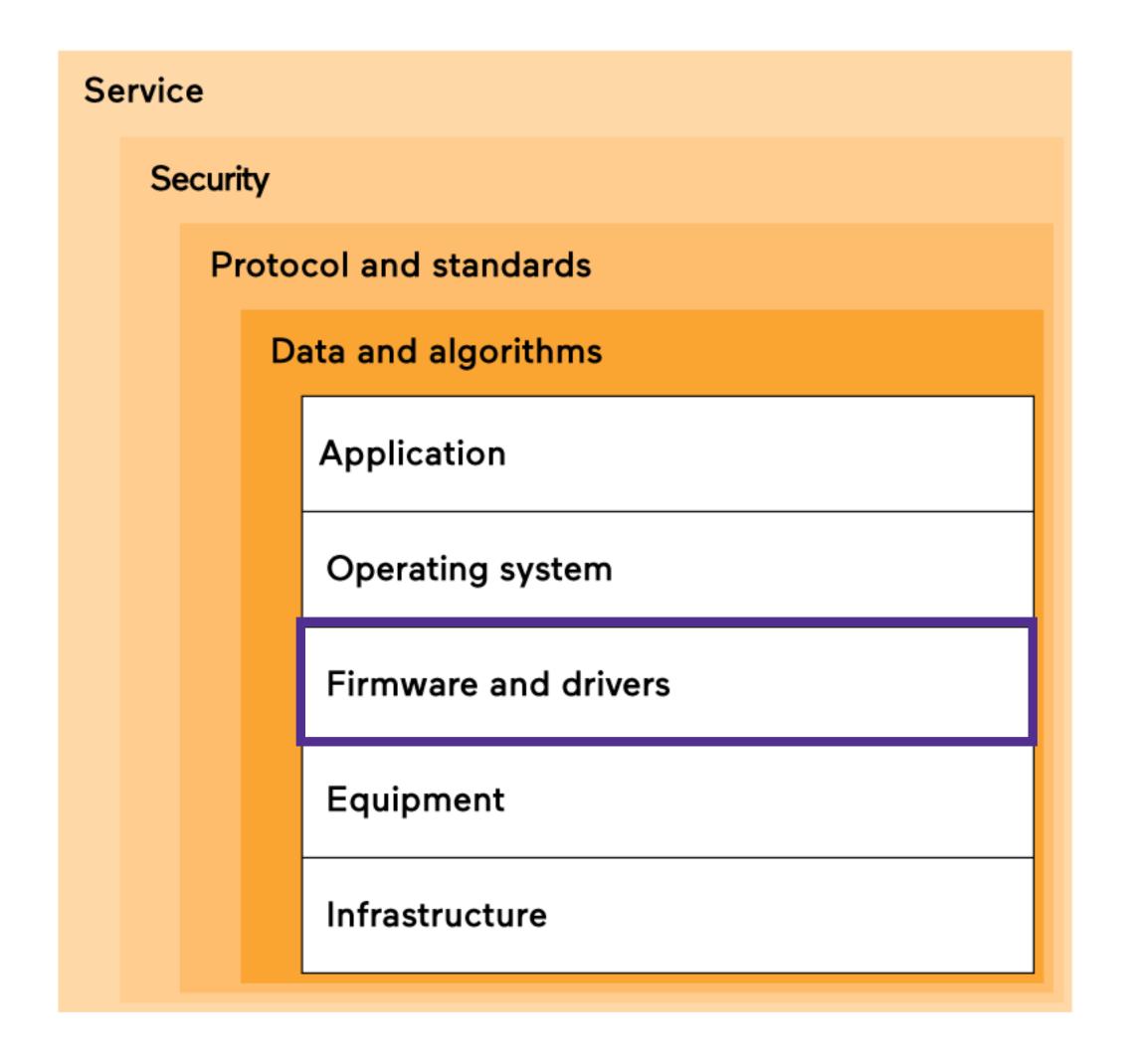


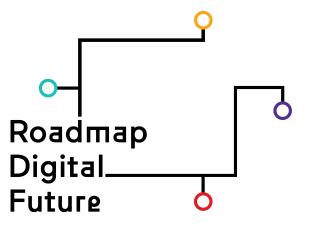


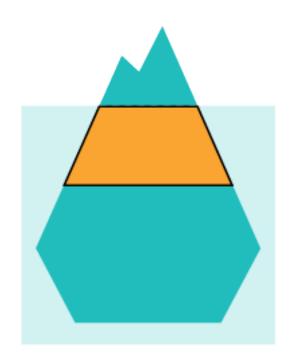


technological stack firmware and drivers

"If you own a device you should have the right to change its firmware and drivers"

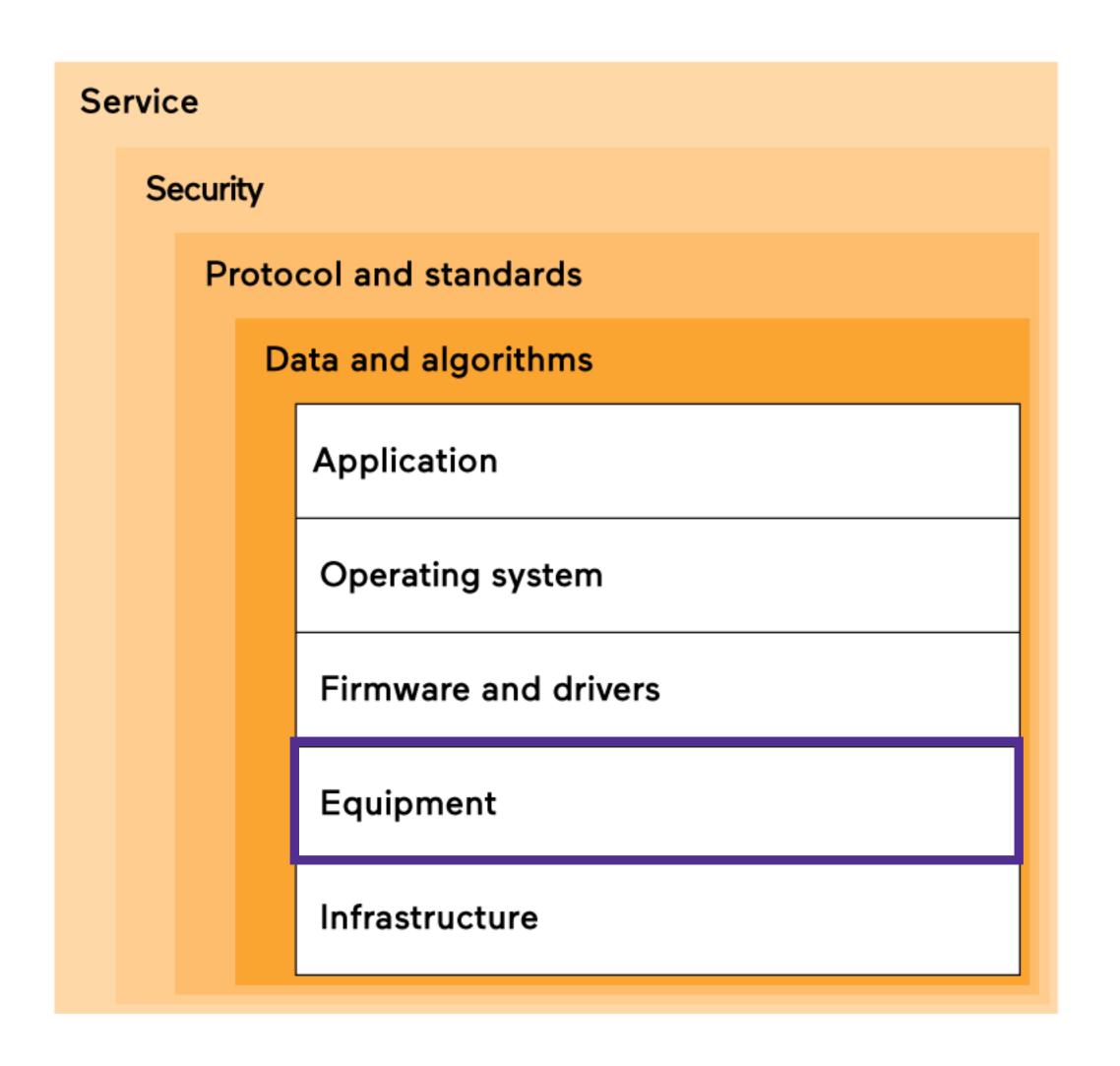


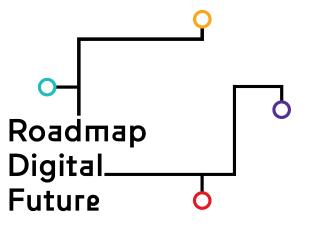


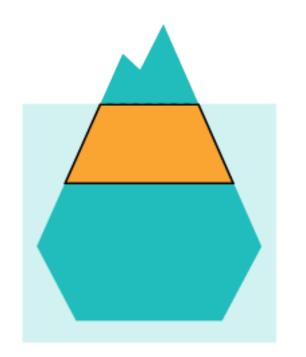


technological stack equipment

"We should all be able to know the origins of the raw materials in our devices"

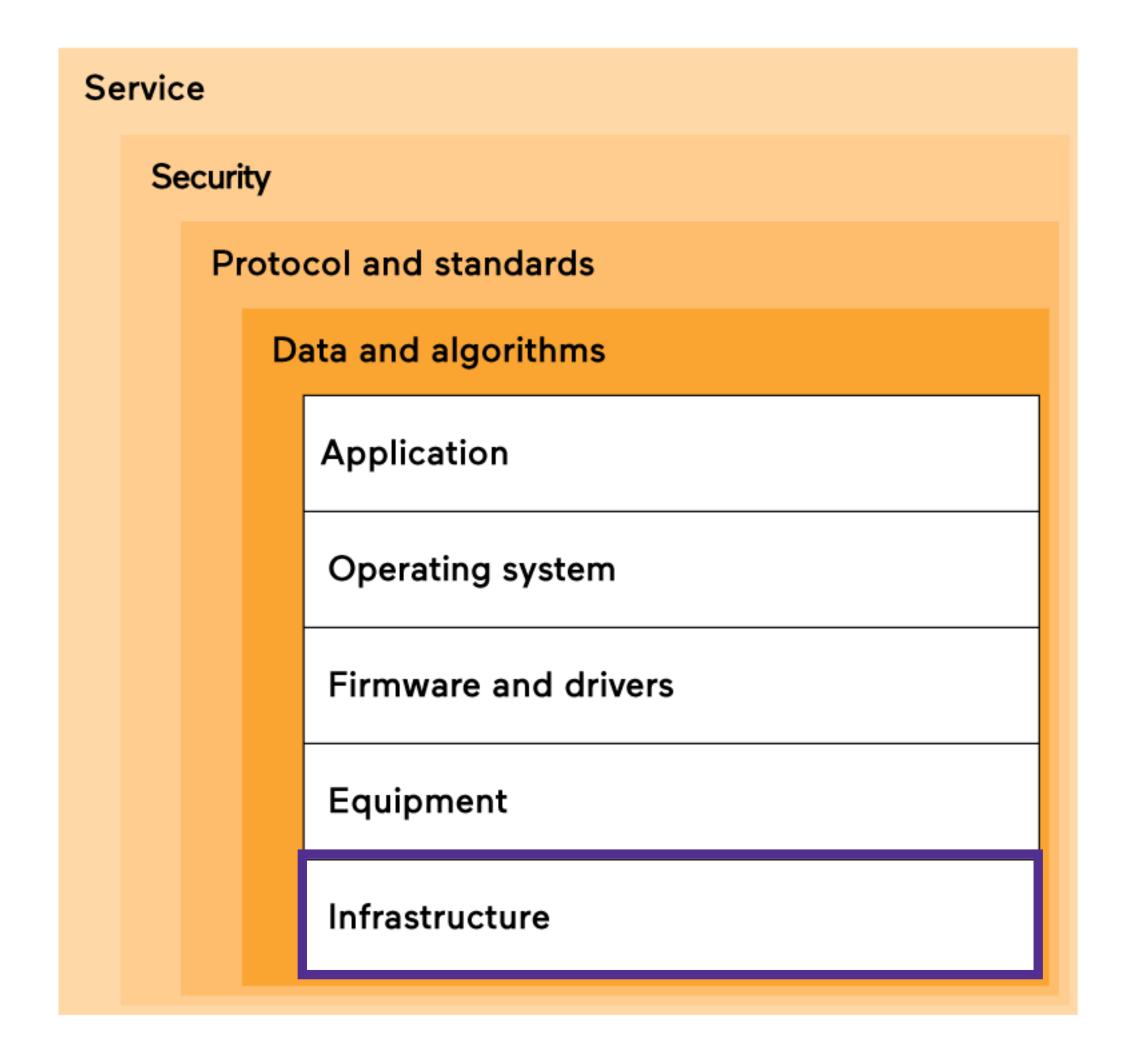


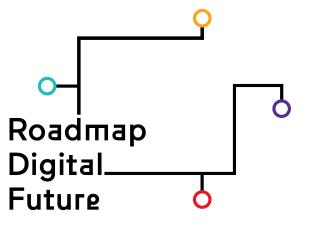


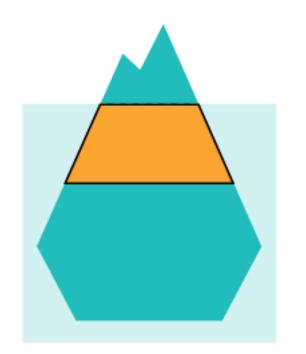


technological stack infrastructure

"Internet infrastructure is a public utility and should be governed accordingly"



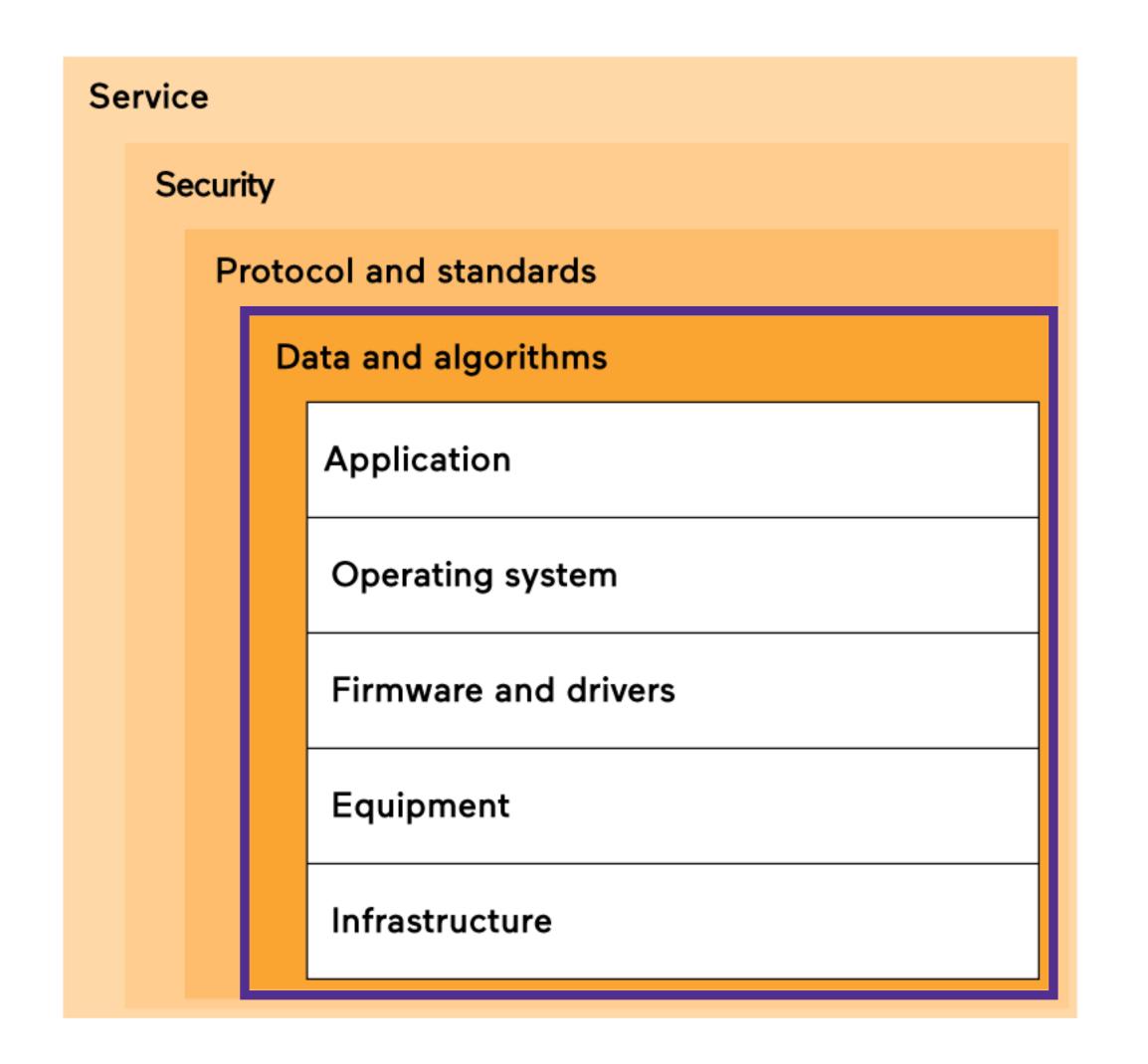


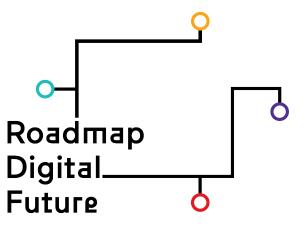


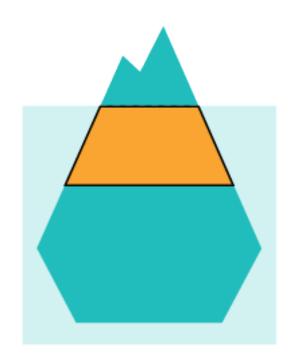
"People should be in control over the data and algorithms that concerns them"

technological stack

contextual layer: data and algorithms



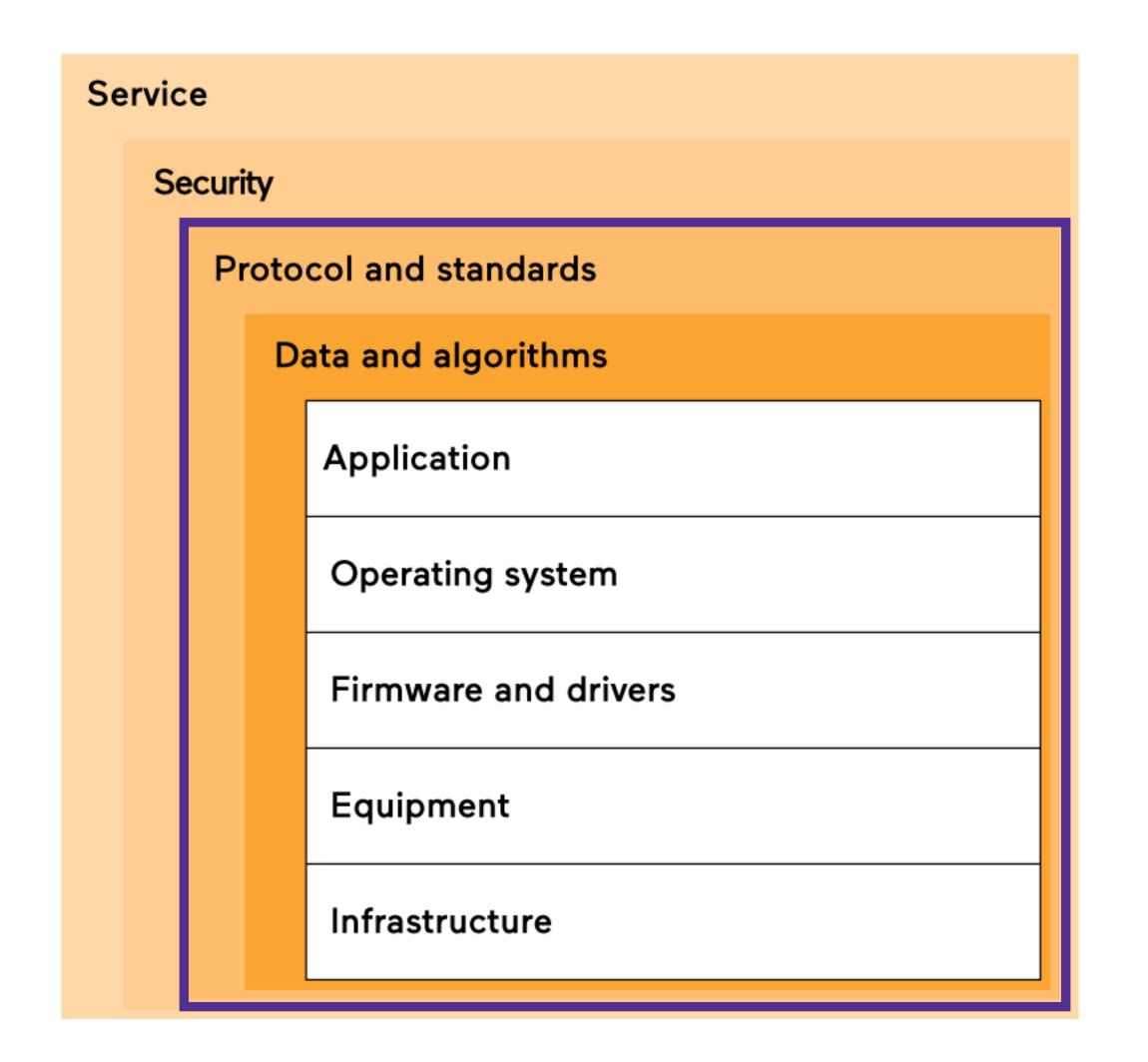


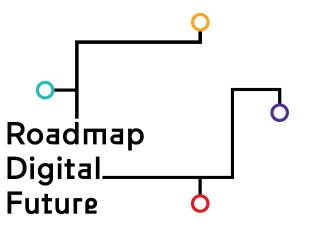


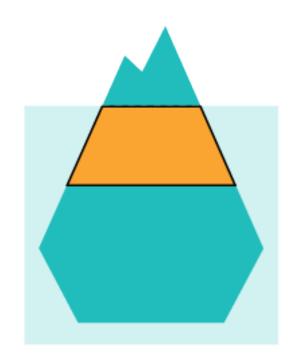
"Standards should be developed openly so anyone can adopt them and guarantee open ecosystems"

technological stack

contextual layer: protocol and standards



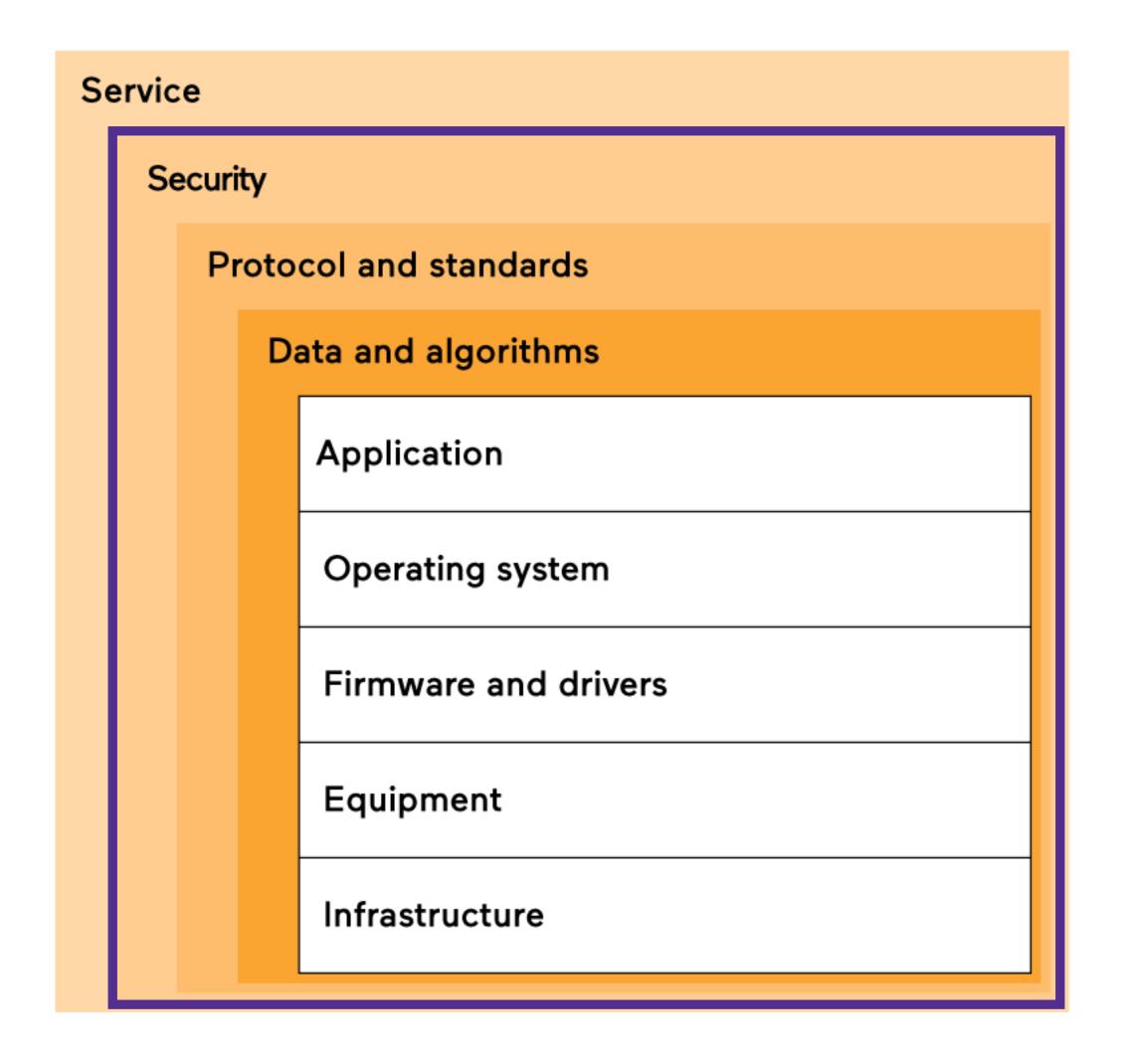


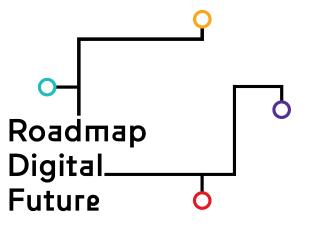


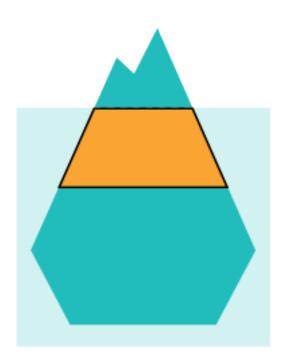
technological stack

contextual layer: security

"Technology should be secure so that we can rely on it safely"



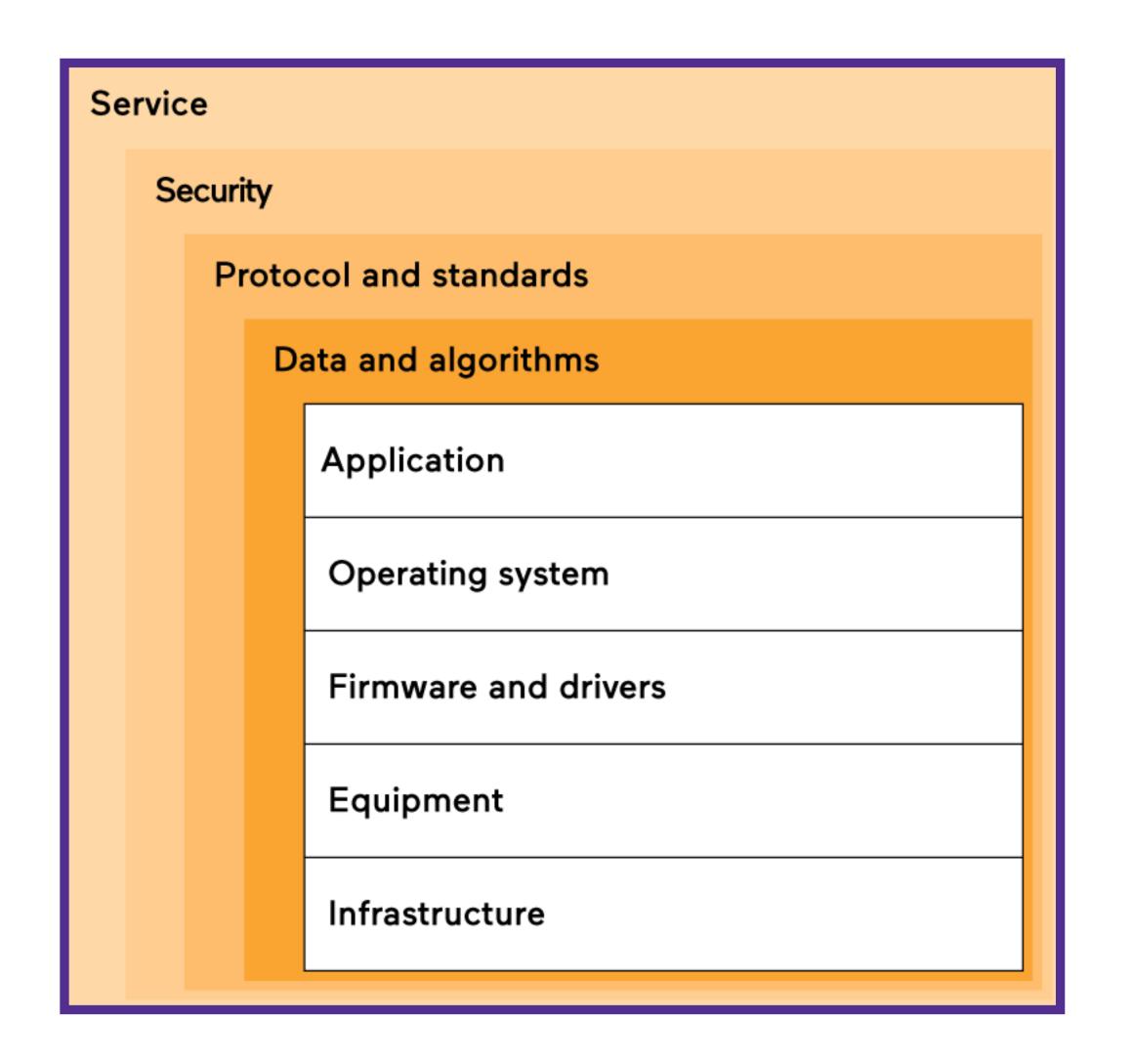


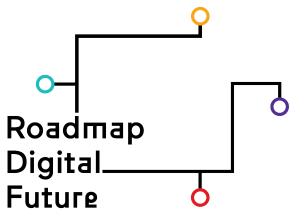


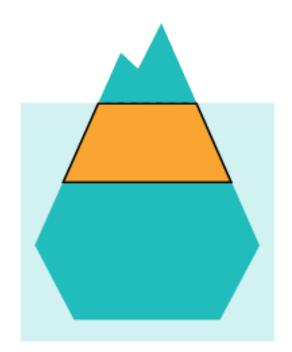
"When we use a service we should be able to look inside the black box"

technological stack

contextual layer: service

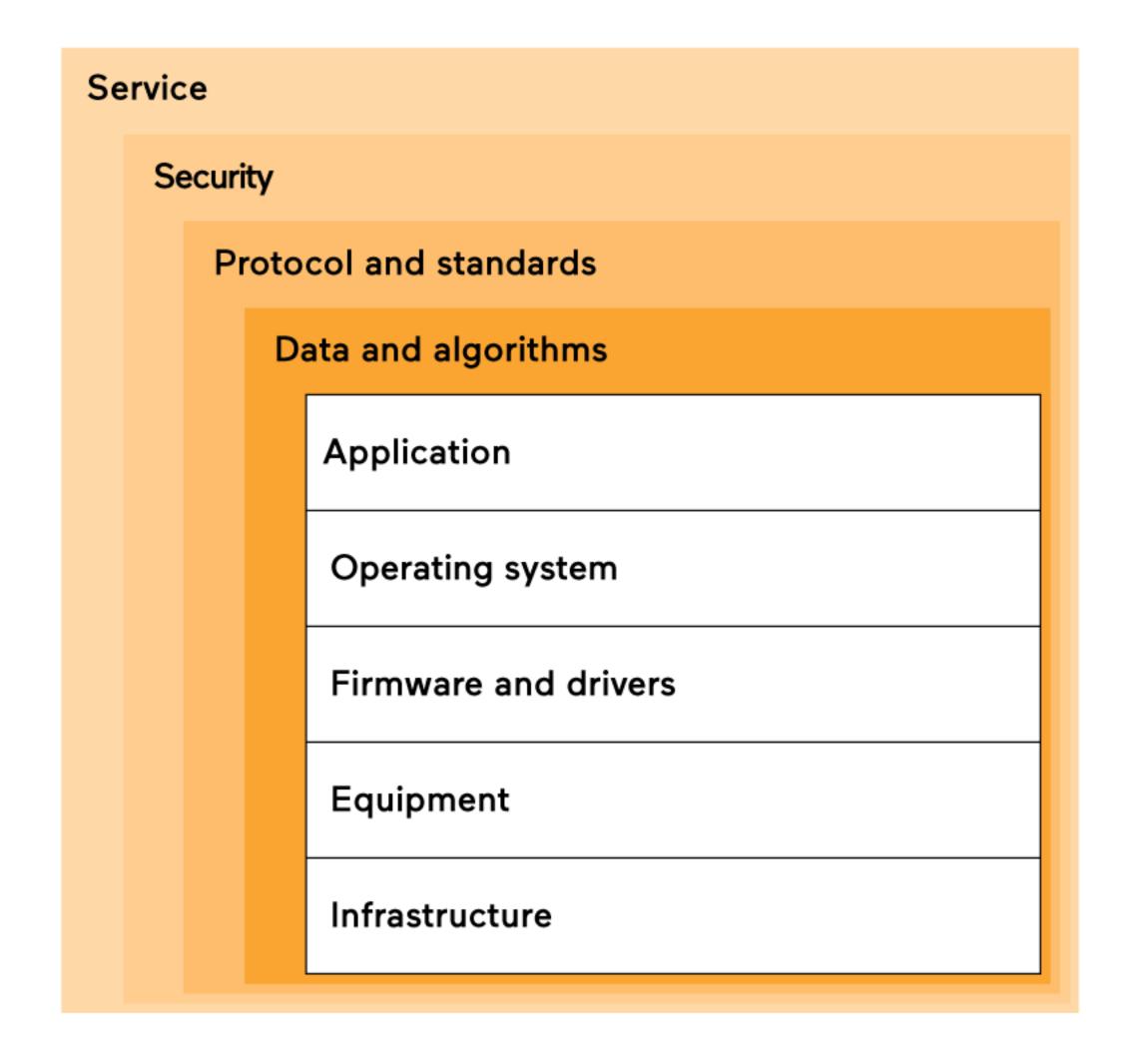


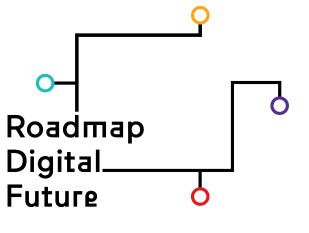


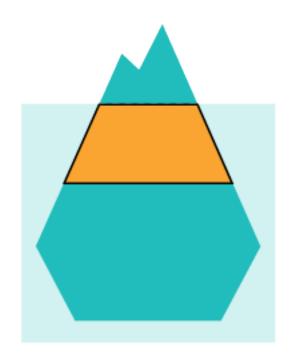


technological stack

public principles,
rule of law
in all layers of the
stack

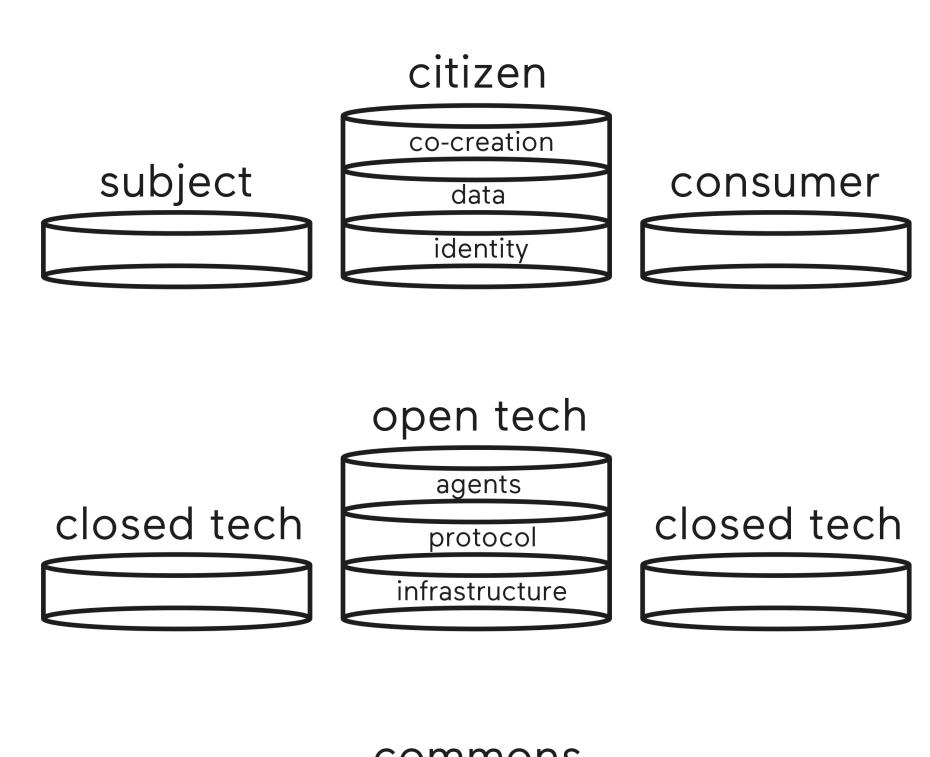


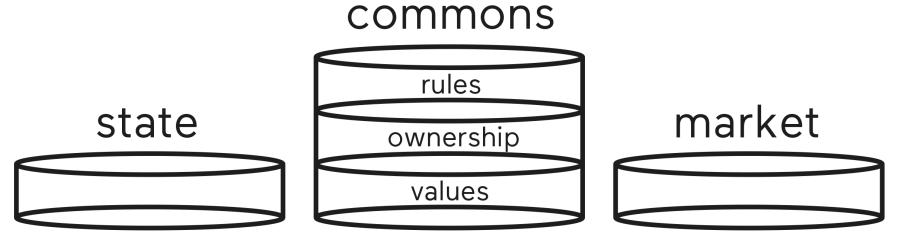


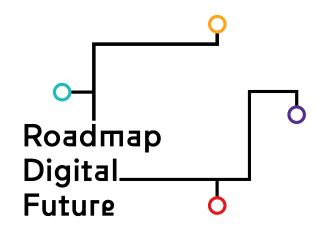


state public private stack stack stack

Is the stack state owned, privately owned or public?







commons are shared resources, maintained and/or created by a community, organised around commonly defined shared rules

Nature

Air...water...dna...photosynthesis...seeds...topsoil...airwaves...minerals... animals...plants...antibiotics...oceans...fisheries...aquifers...quiet... wetlands...forests...rivers...lakes...solar energy...wind energy...

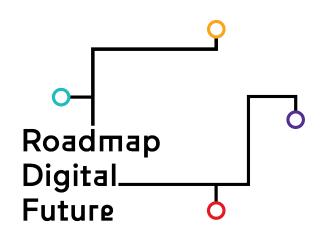
Community

Streets...playgrounds...the calendar...holidays...universities...libraries...museums... social insurance...law...money...accounting standards...capital markets... political institutions...farmers' markets...flea markets...craigslist...

Culture

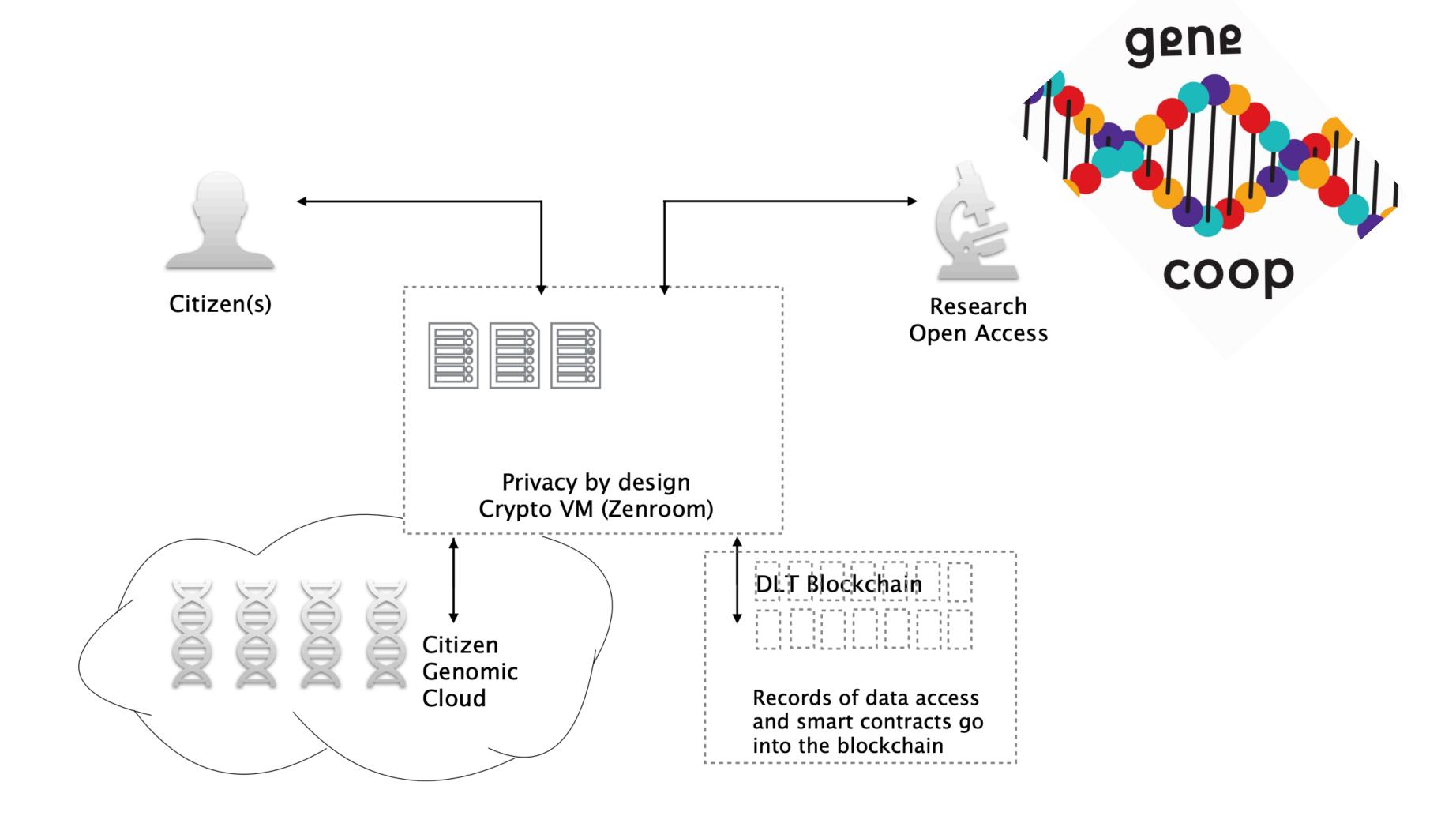
Language...philosophy...religion...physics...chemistry...musical instruments... classical music...jazz...ballet...hip-hop...astronomy...electronics...the internet... broadcast spectrum...medicine...biology...mathematics...open source software...





data commons example:

gene coop citizen genomic data cooperative

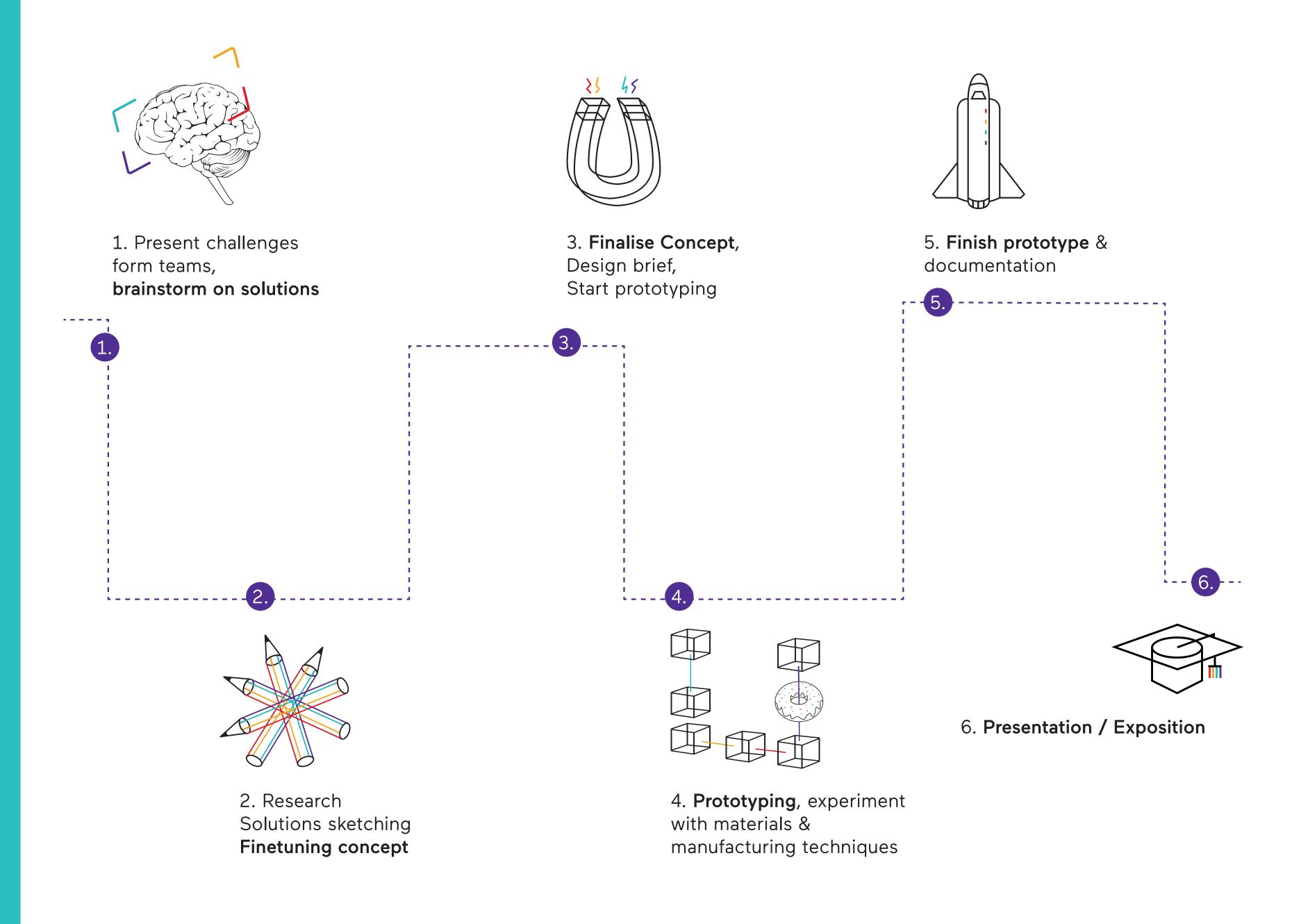


Lucas Evers/Dr. Stefano Bocconi Waag - Technology & Society / Open biotechnologies Dr. Wieke Betten - Radboud University / Health data technologies & ethics Peter Walgemoed Carelliance / Health data governance technology programming

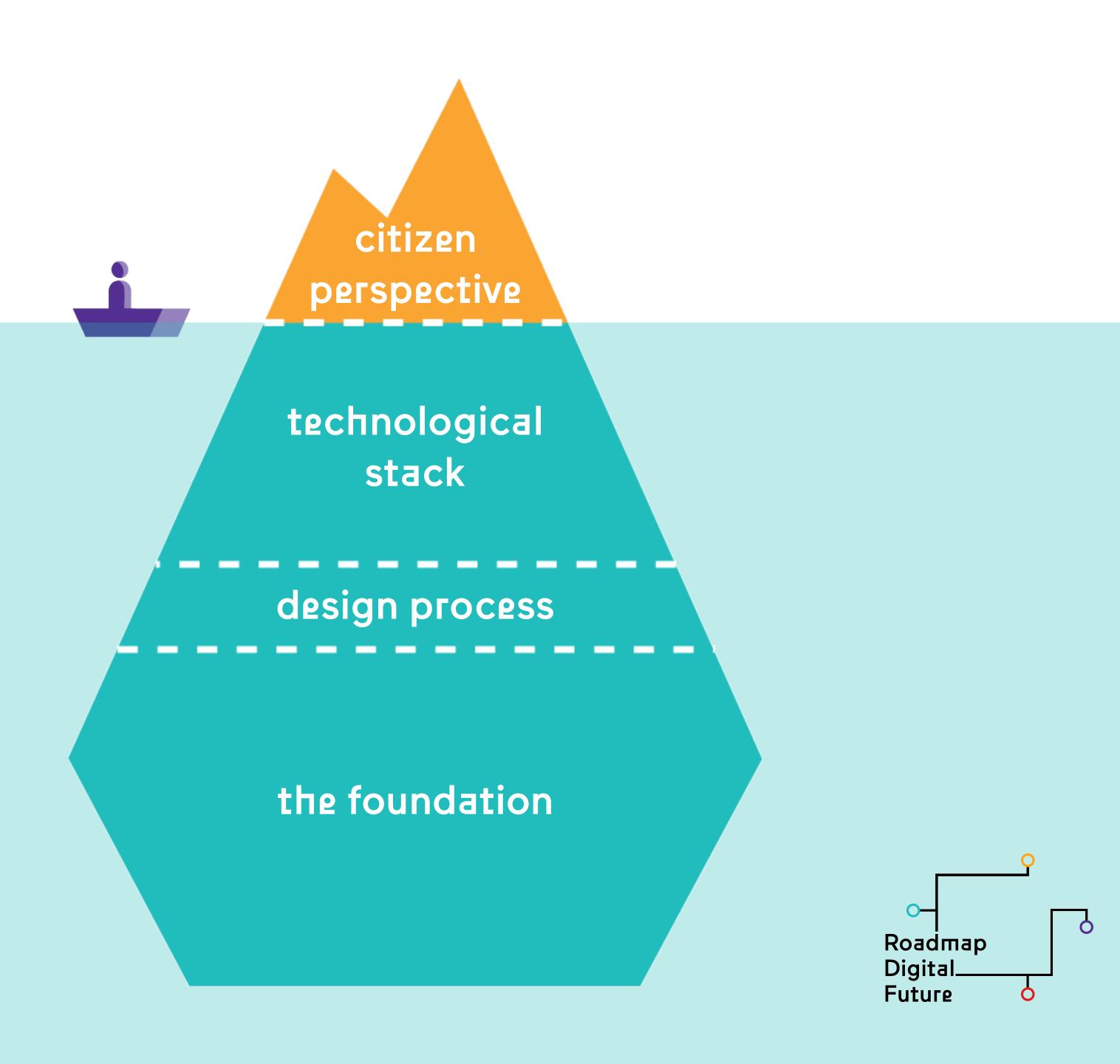
Make Health

open solutions for DIY tools





save and just (digital) future









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