

Patient advocacy revised

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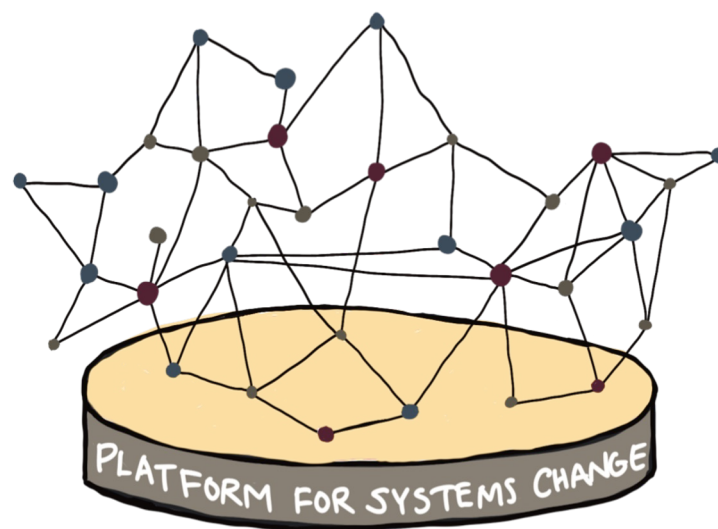


Agenda

15 min: Presentation

35 min: Workshop

10 min: Closure



Why?

Move beyond traditional advocacy

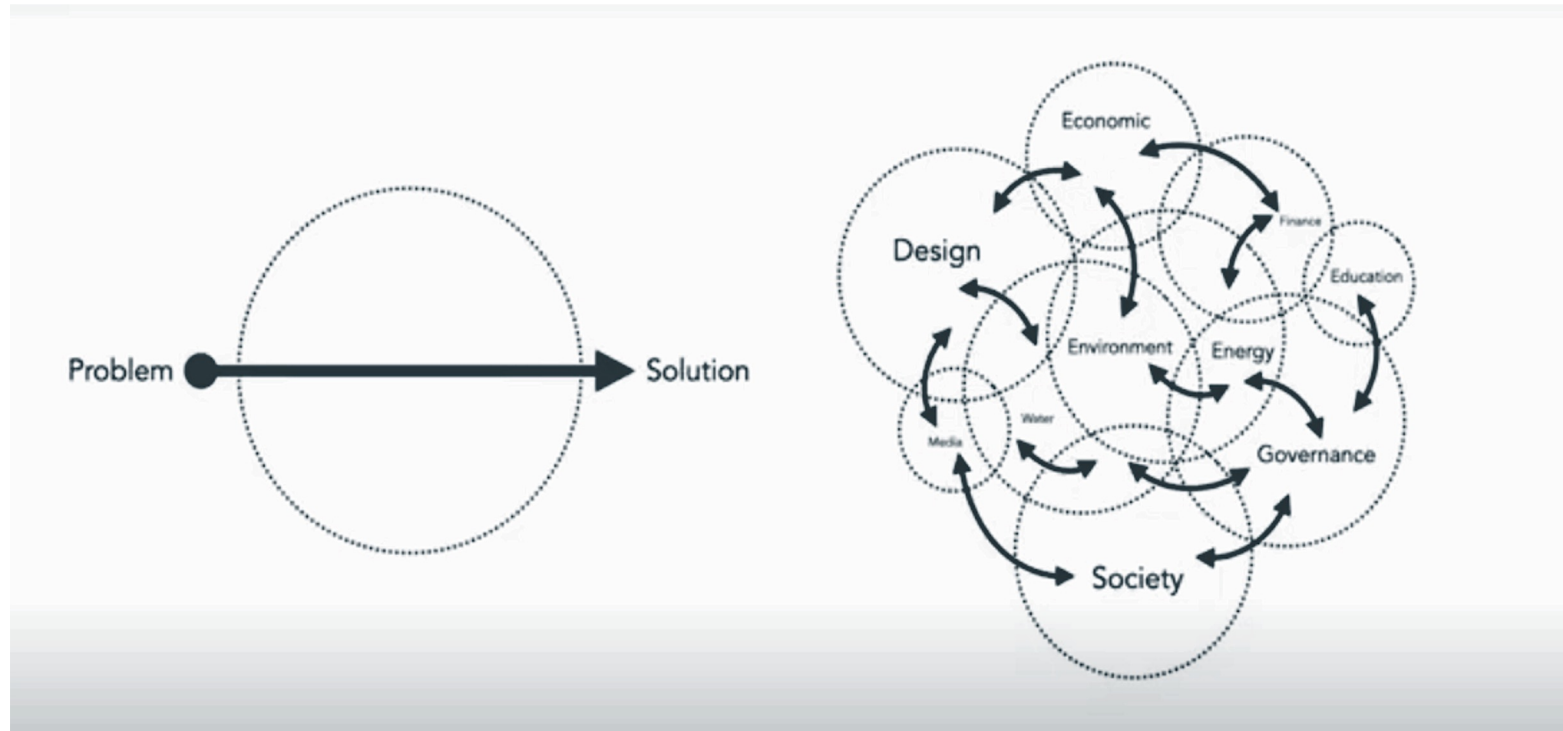


Pace of change is too high for reactive advocacy to succeed

There are too many unknowns for proactive advocacy to work

The advocacy asks will be too many to be fulfilled

What brought us here, won't
alone get us there



collaboration
diagnosis
strategy
innovation
leadership & learning

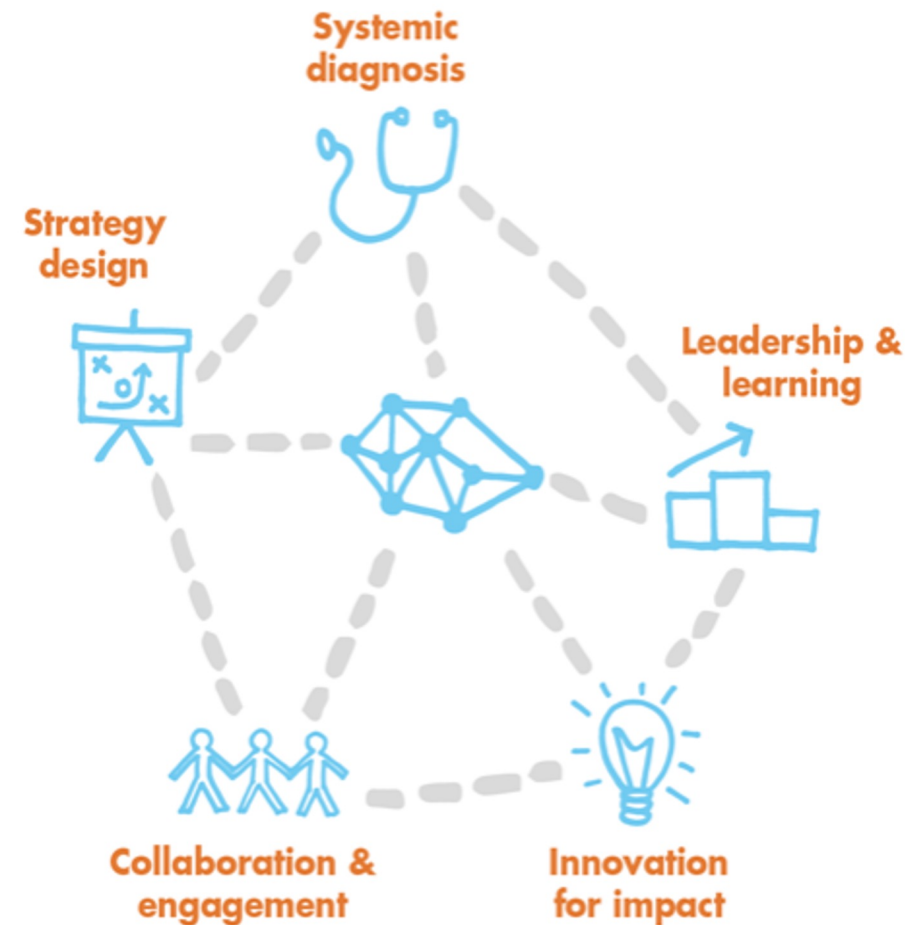


Image source: Forum for the future

“Seeing” the system

Mindset Shifts

from an **outside observer** → to **being part of a system**

from **internal taxonomies** → to **externals dynamics**

from **predetermined & internal solutions** → to **understanding emergence in the system**

Competency Framework for System
& Portfolios Approaches for Teams

Tackling Complex Problems

Generating new possibilities

Mindset Shifts

from **solutions** → to **options/interventions**

from **funneling** → to **layering**

from **results cost/benefits** → to **effects opportunities**

Building collective will to transform

Mindset Shifts

from **technical** → to **political**

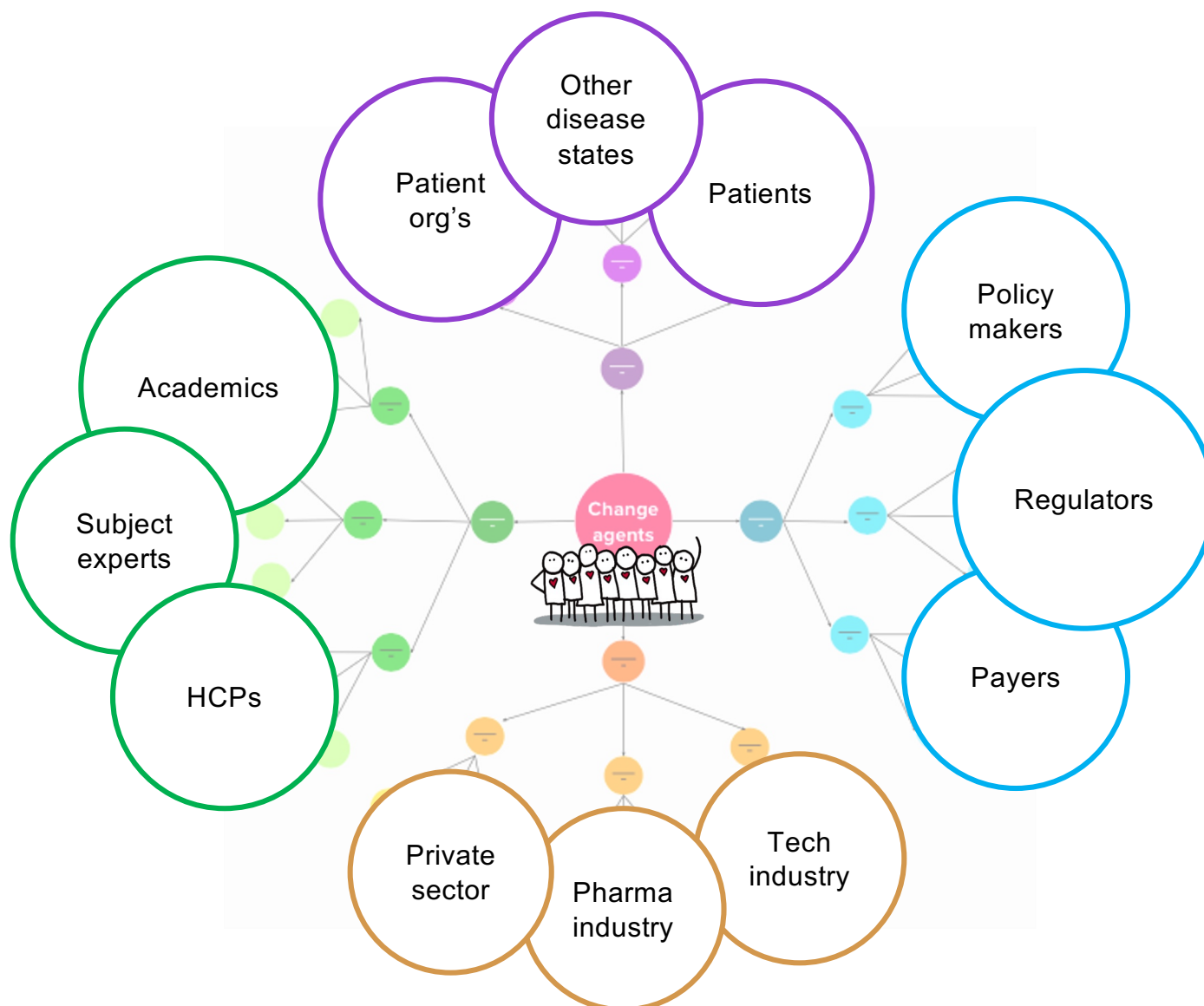
from **fixing** → to **reframing**

from **destination** → to **direction**



[Portfolio approach]

Source: <https://medium.com/@undp.innovation/building-capacity-for-strategic-innovation-an-emerging-competency-framework-for-portfolio-work-fadb768242be>



So what?

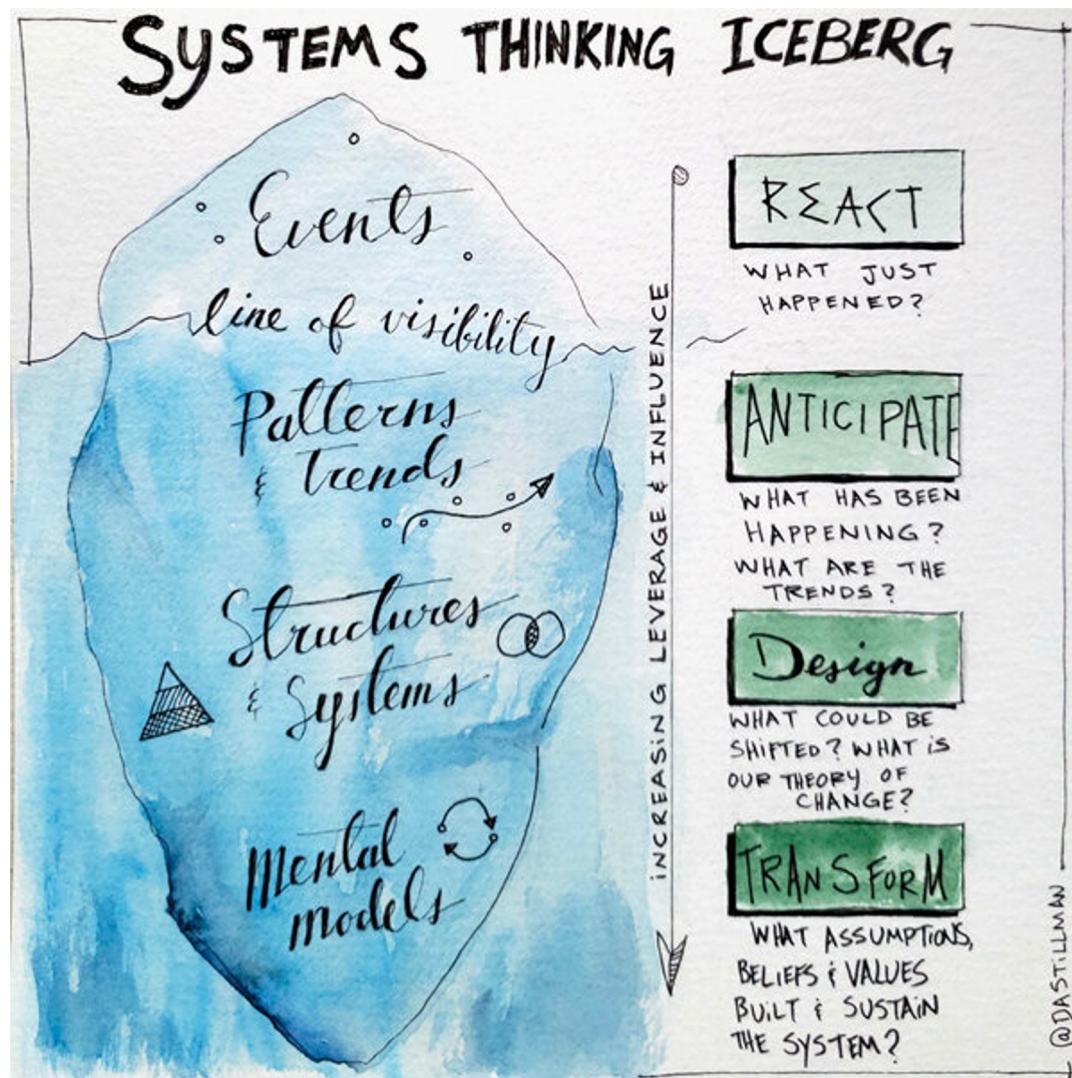
“The best way to predict the future
is to create it”

Abraham Lincoln



- Establishing new ways of addressing issues
- Establishing new ways of working together
- Establishing new relationships
- Acknowledging human behaviour
- Creating a new narrative about patients and the role of patient organisations

Workshop

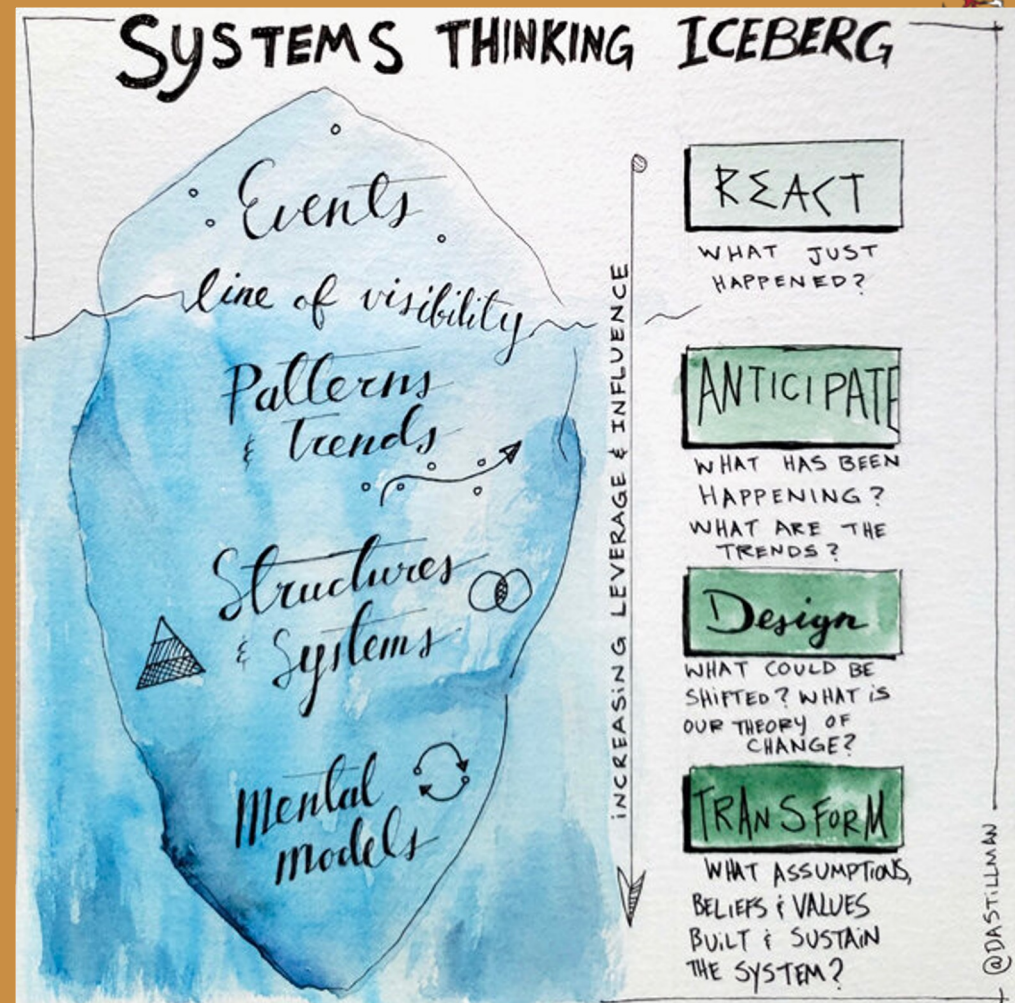


Events: you missed the bus this morning

Patterns of behaviour (what has been happening over time): you missed the bus three times last week

Systems structure (what is influencing the repeating behavior): you woke up late, your bag wasn't packed, you couldn't find your keys, you spilt coffee on your pants, you waited for the elevator, many pedestrian at the street in the morning, you had to run, there was a red light, ticket machine didn't work

Mental models (what beliefs stimulate the behaviour): you don't like to wake up in the morning, you overestimate how fast you run, you think you can't survive without a coffee, you can't see the problem in being 30 min late,



Theme ideas to dive into

- Uncover why we are losing members in the NMO
 - Uncover why not all patients have access/go to a haemophilia treatment or comprehensive care centre
 - Uncover why diversification of funding is difficult
 - Uncover why there is no national patient registry with all patients
 - Uncover why optimal treatment is missing for example (pick one) von Willebrand, other factor deficiencies, Bernard-Soulier syndrome, Glanzmann thrombasthenia
 - Uncover why women with bleeding disorders are diagnosed later than men
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Closure

Free float writing



#1: Find a pen and paper

#2: Sit in a way that you can write

#3: When the music starts, please begin to write

#4: If you get stuck you can start your sentence with: *In our community, I aspire to make a change...*

#5: When the music stops, please stop writing

Music

Thank you and now
time for lunch!