



Symptomatische gewrichtshypermobiliteit in kinderen en jongeren

"Perspectieven vanuit de kliniek en Artificial Intelligence"

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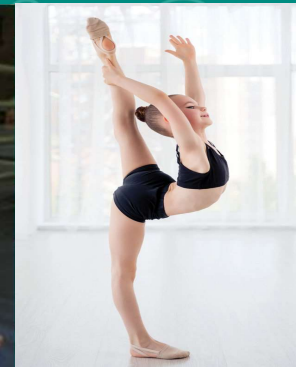
Professor Data technology in health and healthcare

(pediatric) physical therapy (Hogeschool Rotterdam)

Research lead Data Supported Healthcare

Founder National Center of Expertise Ehlers-Danlos (ErasmusMC)

Senior investigator Medical Delta, Livinglab Better in Better Out oncology



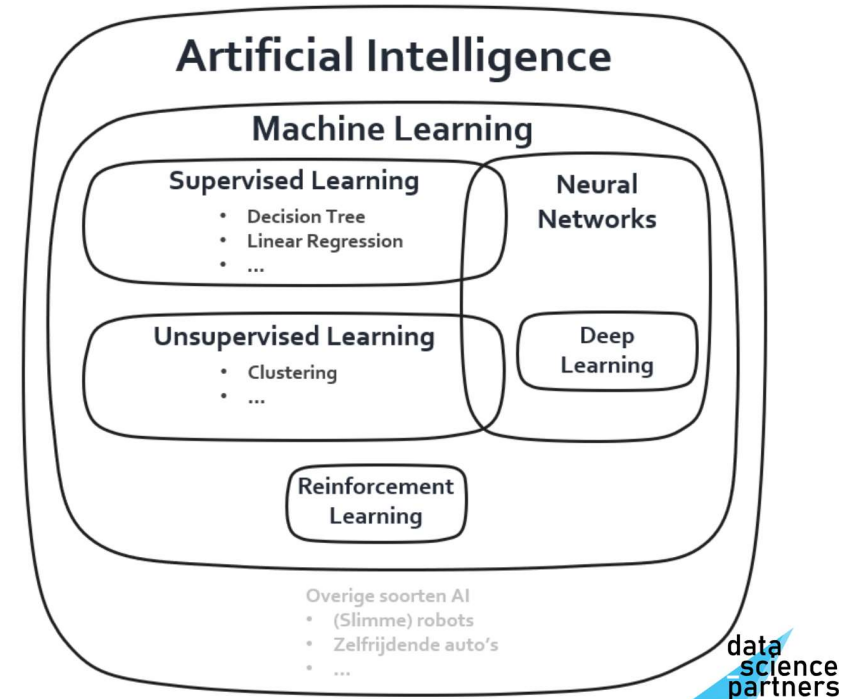
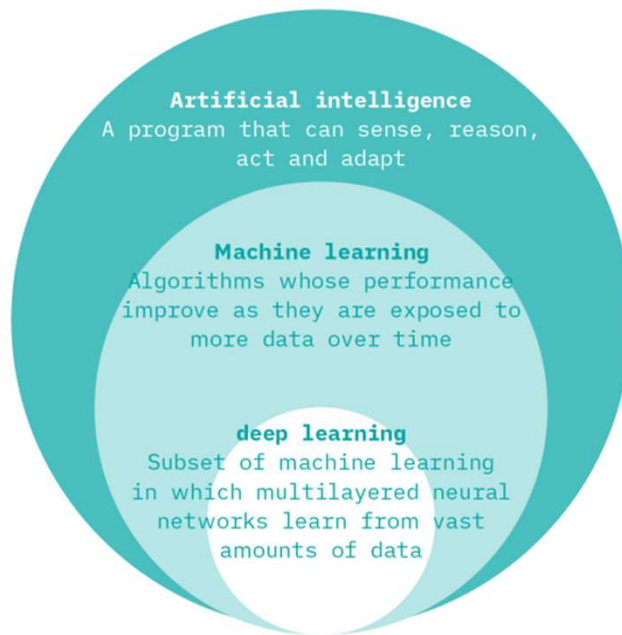


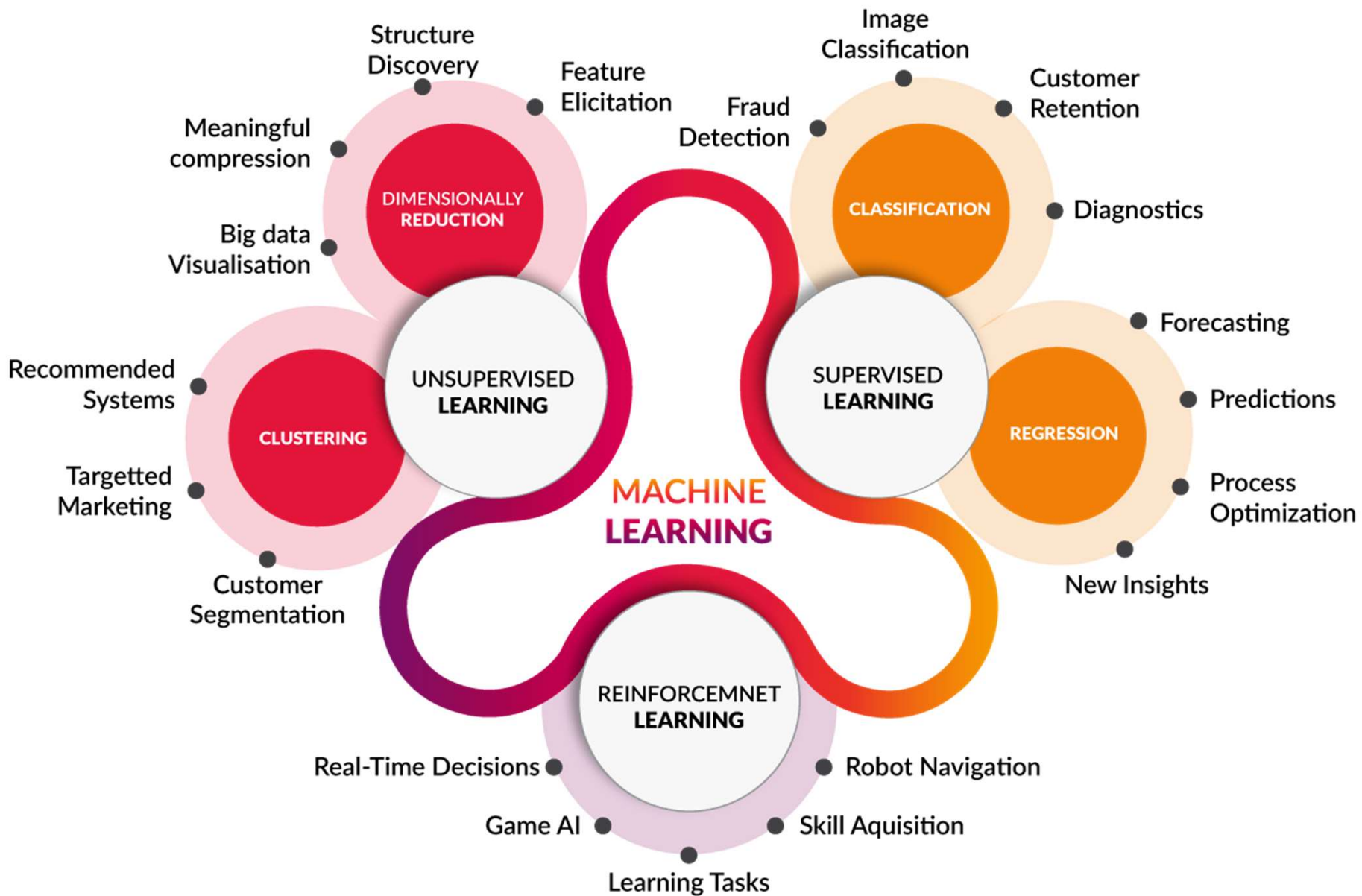
De data gedreven maatschappij

- Data continue gecreëerd en verzameld
- Data als “natuurlijke” grondstof
- Data gedreven applicaties en ontwikkeling (data-science)
- Verantwoord gebruik van data
- Data eigenaarschap en gebruik als onderdeel van de mensen rechten
- Een fysieke en een digitale identiteit en realiteit



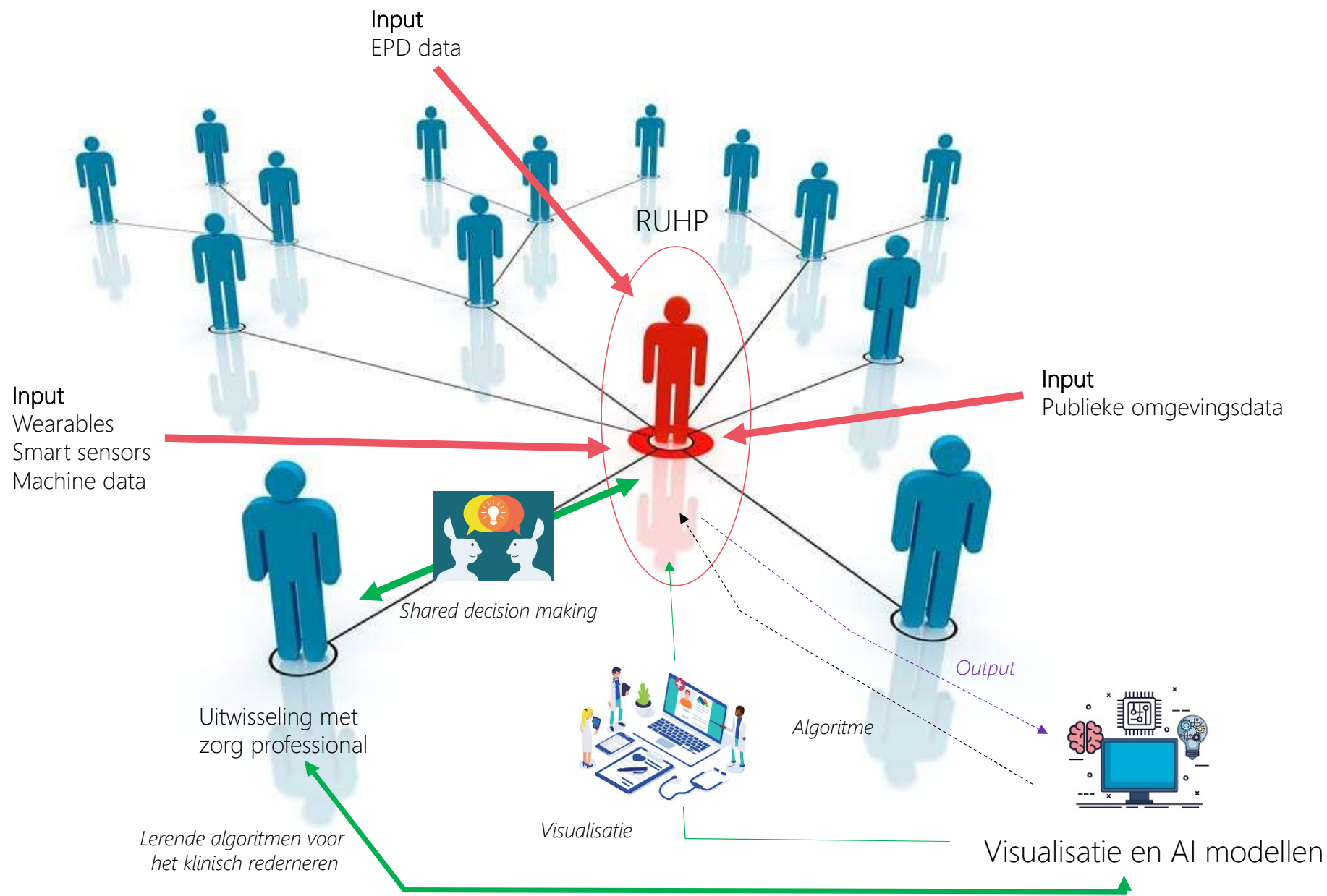
Artificial intelligence







Rotterdam Urban Health Platform



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Perspectief 1

chronisch ziek zijn bij jongeren en comorbiditeit

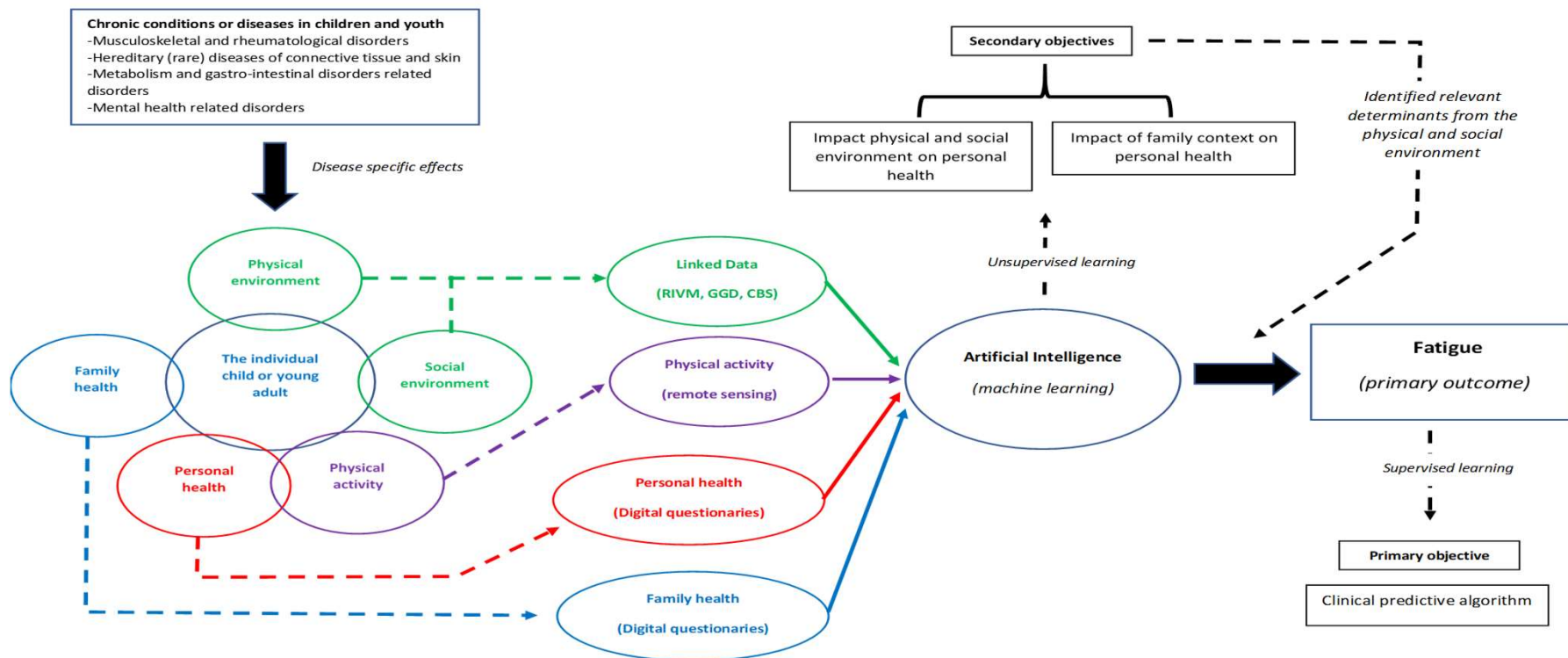
Deel 9



Basis data-architectuur project ACT4FATIGUE

Figure 1

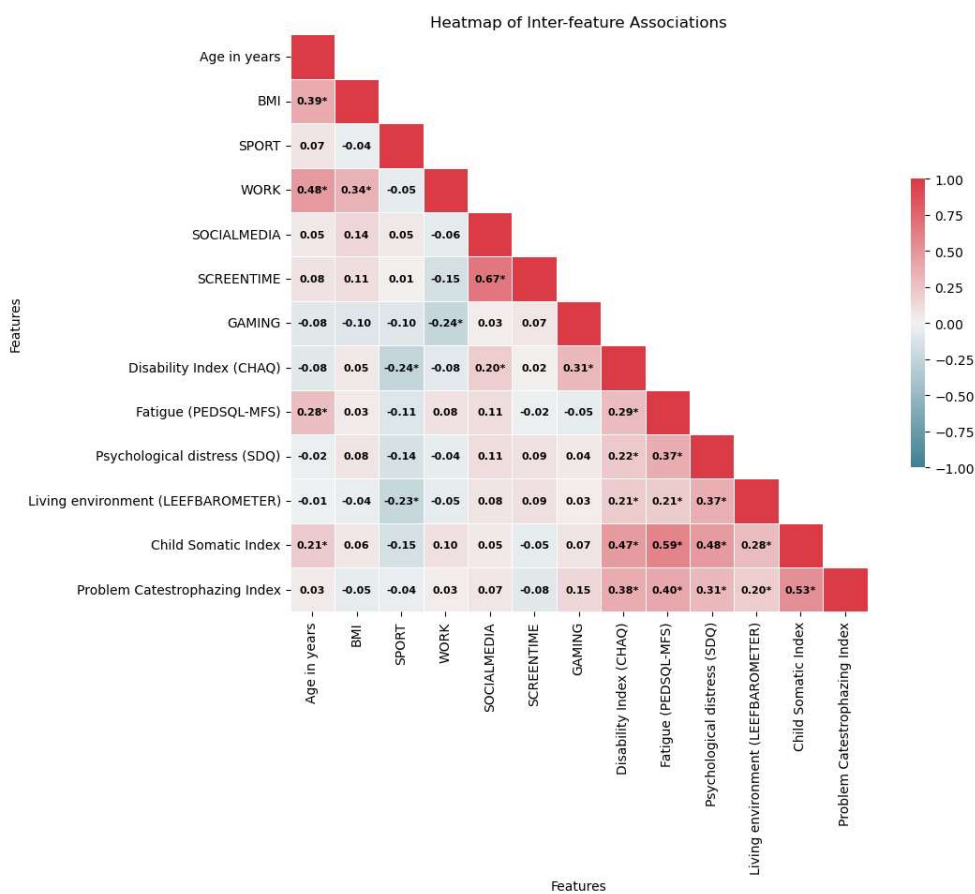
Theoretical framework study (modified from the ICF)



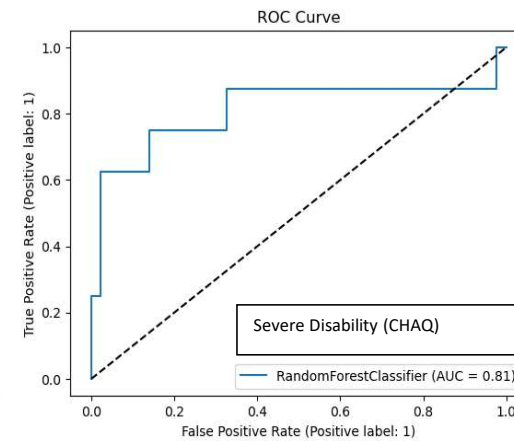
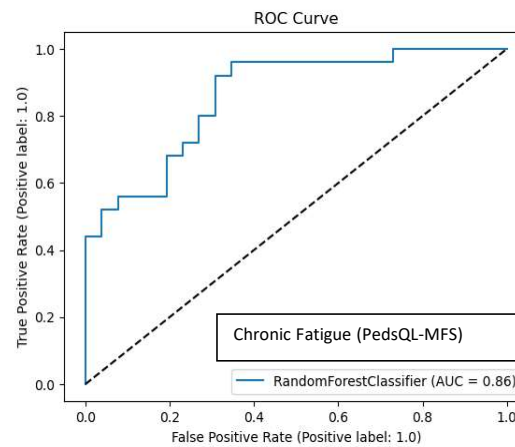
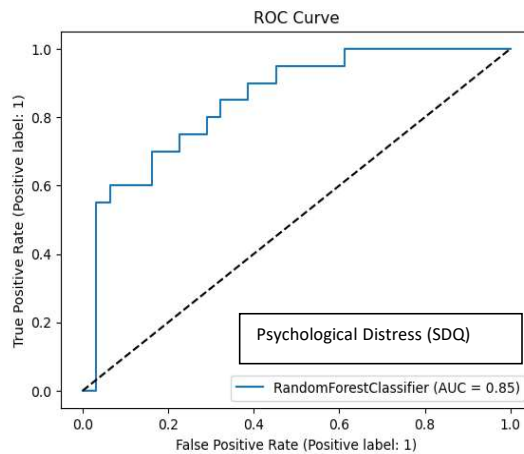
Comorbiditeit voorspellen bij chronische ziekten en de impact van de leefomgeving

- 350 jongeren met chronische ziekten
- “Community dwelling: geen actieve behandeling”
- Meer dan 1 jaar chronische klachten
- Geen terminale ziekten

Hoge mate van complexe relaties tussen diverse factoren over het gehele ICF



ML model 1: comorbiditeit



Precisie (Random Forest)

Psychologische comorbiditeit: 85 van de 100

Chronische vermoeidheid: 86 van de 100

Ernstige beperkingen: 81 van de 100

De impact van fysieke en sociale leefomgevingen op gezondheid

Slechte leefbaarheid geeft een grotere kans op:

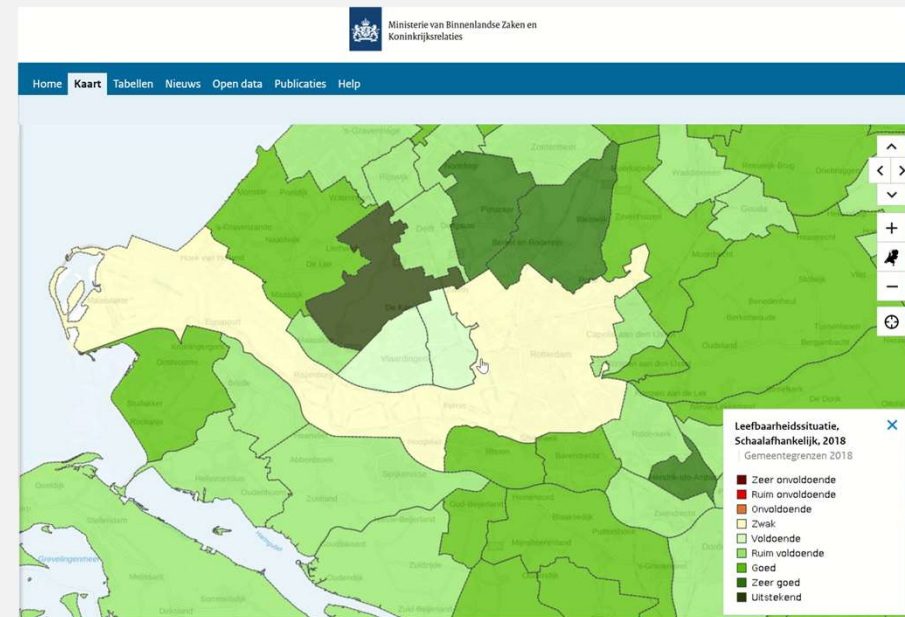
Mentale gezondheidsproblemen (6-29x zo groot)

Chronisch vermoeidheid (4-12x zo groot)

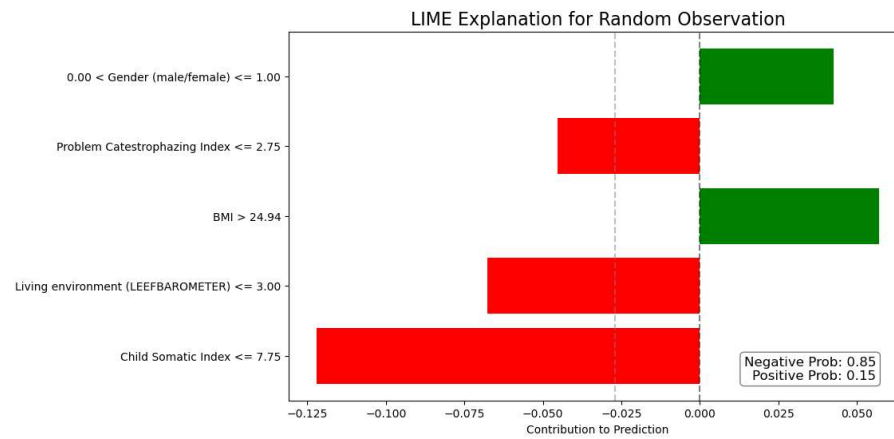
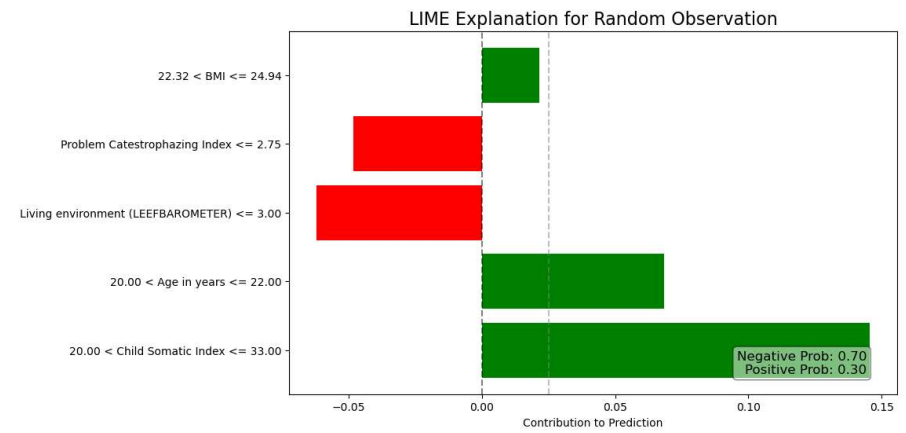
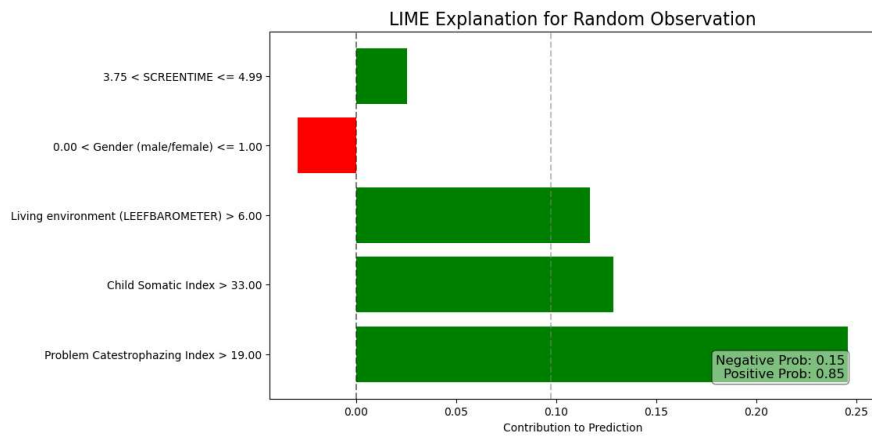
Zware fysieke beperkingen (4-20x zo groot)

Niet een patroon: veiligheid, voorzieningen, bewoners

Wel: Staat woningen, vervuiling (licht, geluid, stoffen)



Onderliggende factoren (aldus AI model)



Perspectief 2

Klinische patronen van hEDS/HSD bij kinderen volgens AI

Deel 9



Comparisons over groups

	Other Chronic Disease			Symptomatic GJH			P-value
	Mean (SD)	Min	Max	Mean (SD)	Min	Max	
Age	17.9(4.1)	8	24	16.6(3.3)	9	23	.021
BMI	22.2(4.4)	14.2	40.9	24.0(6.5)	15.3	47.7	.067
Pain VAS (mm)	25.3(18.8)	0	87	49.6(11.1)	0	100	<.0001
Somatic Symptoms and severity	19(16)	0	87	35(12)	1	68	<.0001
Total Fatigue (PEDSQL-MFS)	57(21)	0	100.0	49(19)	15	97	<.0001
Total Psychological distress (RCADS)	11(7)	0	33	13(7)	0	29	.029

Symptom profiles

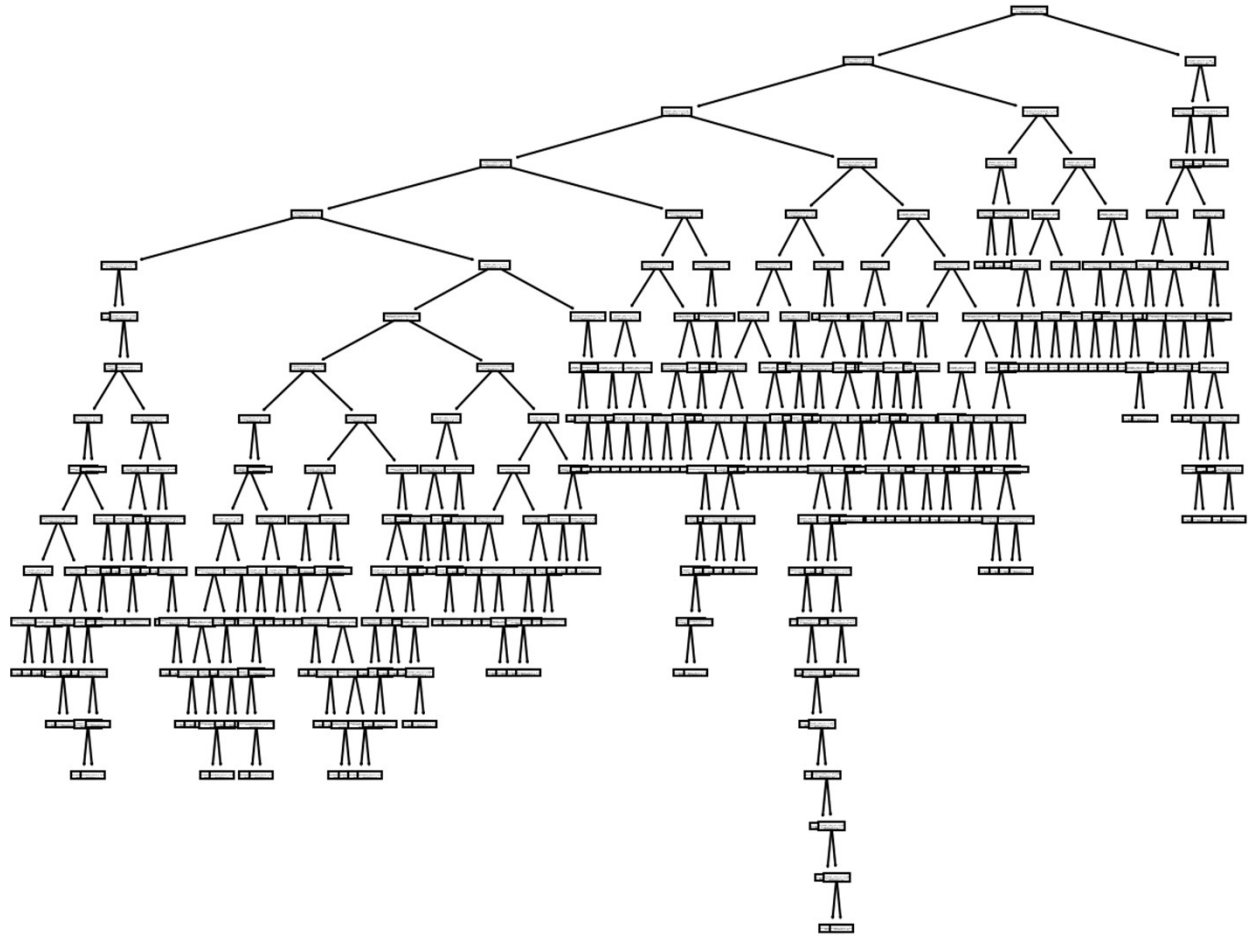
	Absent	Present	Absent	Present	P-value
Chronic Fatigue	64.6%	35.4%	61.7%	38.3%	.709
POTS	50.7%	49.3%	10.6%	89.4%	<.0001
Diarrhoea	67.3%	32.7%	59.6%	40.4%	.397
Constipation	72.6%	27.4%	63.8%	36.2%	.226
Gastro-intestinal issues	56.5%	43.5%	40.4%	59.6%	.045
Wide spread pain	31.4%	68.6%	25.5%	74.5%	.425
Headache and Migraine Symptoms	49.3%	50.7%	51.1%	48.9%	.829
Weakness and Neurological Symptoms	30.9%	69.1%	27.7%	72.3%	.685

Table 1: General demographics and symptom profiles of included population

Data supported decision making in rare diseases

Artificial intelligence kan bijdragen
Aan het beter opsporen van GJH
Gerelateerde ziekten

Beslisboom mbt diagnostiek bij
EDS(5% totaal!)



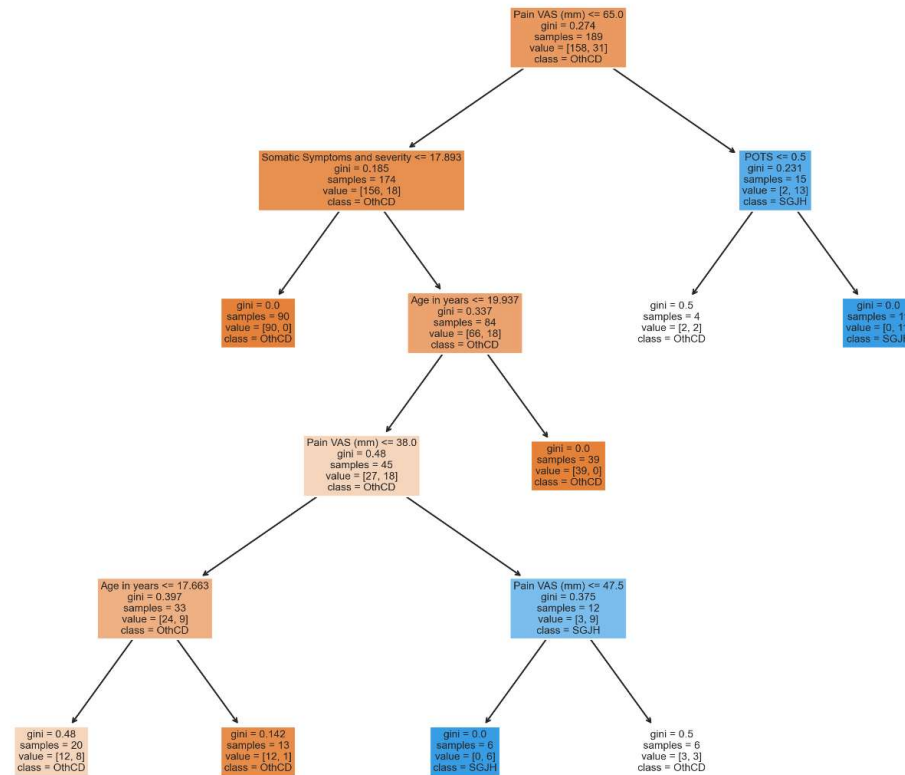
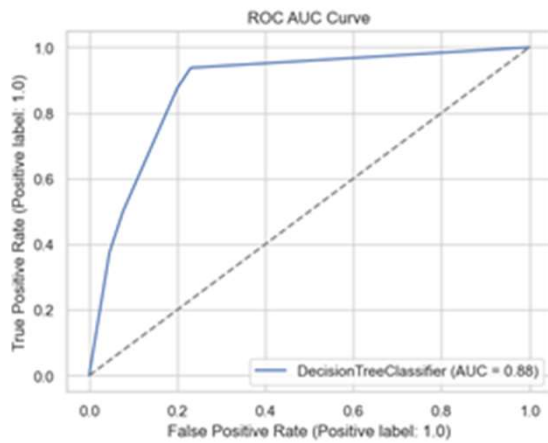
Klinische diagnose hEDS/HSD

Onderscheidende factoren van andere chronische ziekten bij jongeren

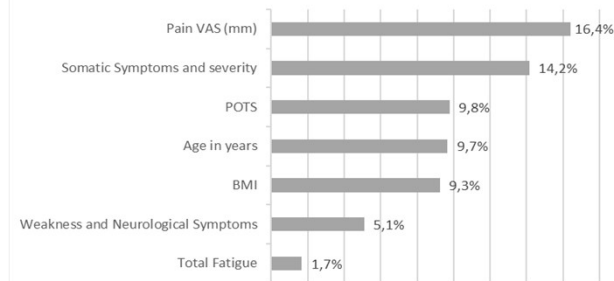
Hoge pijn (VAS > 65mm)
Veel comorbiditeiten
En POTS

Hoog onderscheidend vermogen

Optimized model (CART)

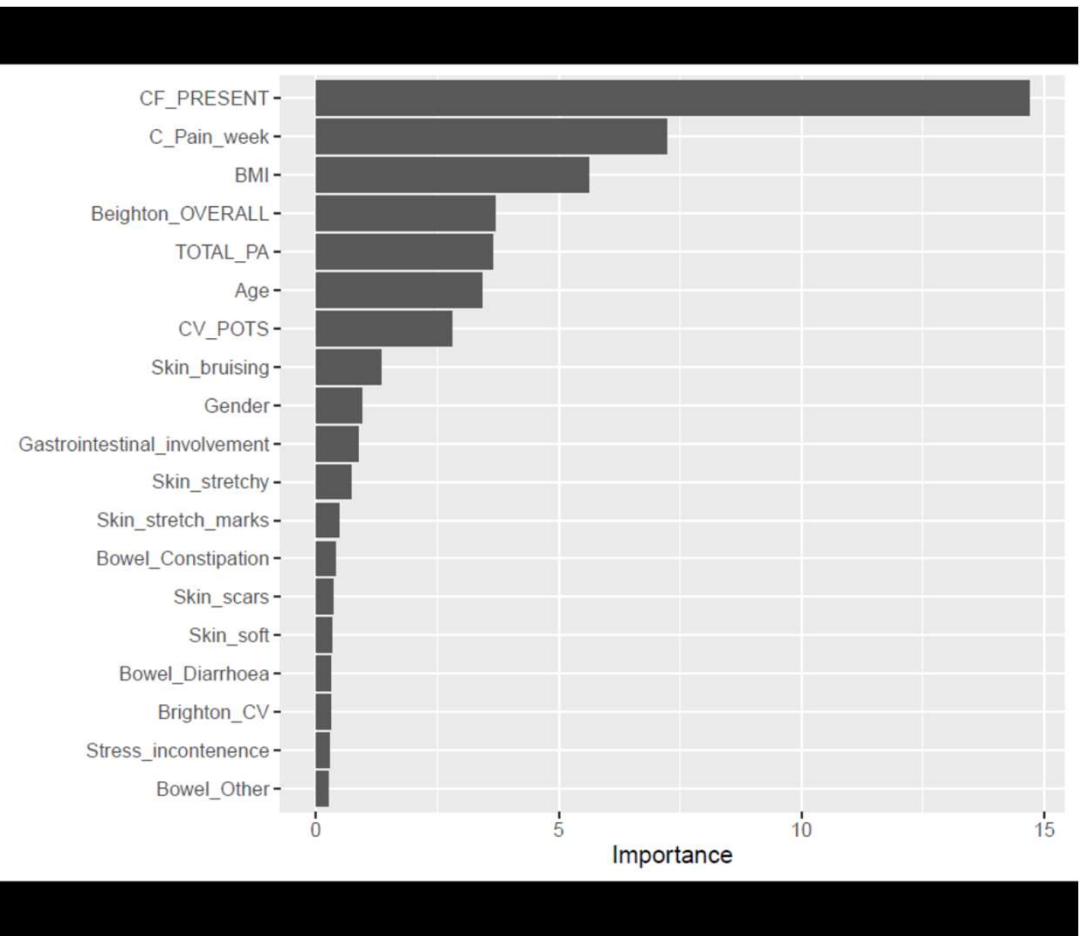


RF-Model



Belangrijkste determinanten beperkingen

Aanwezigheid vermoeidheid
belangrijkste voorspeller invaliditeit



Real world patterns of health inequality and discrimination



Unequal access and resource allocation



Discriminatory healthcare processes



Biased clinical decision making

Discriminatory data



Sampling biases and lack of representative datasets



Patterns of bias and discrimination baked into data distributions

Application injustices



Disregarding and deepening digital divides



Exacerbating global health inequality and rich-poor treatment gaps



Hazardous and discriminatory repurposing of biased AI systems

Biased AI design and deployment practices



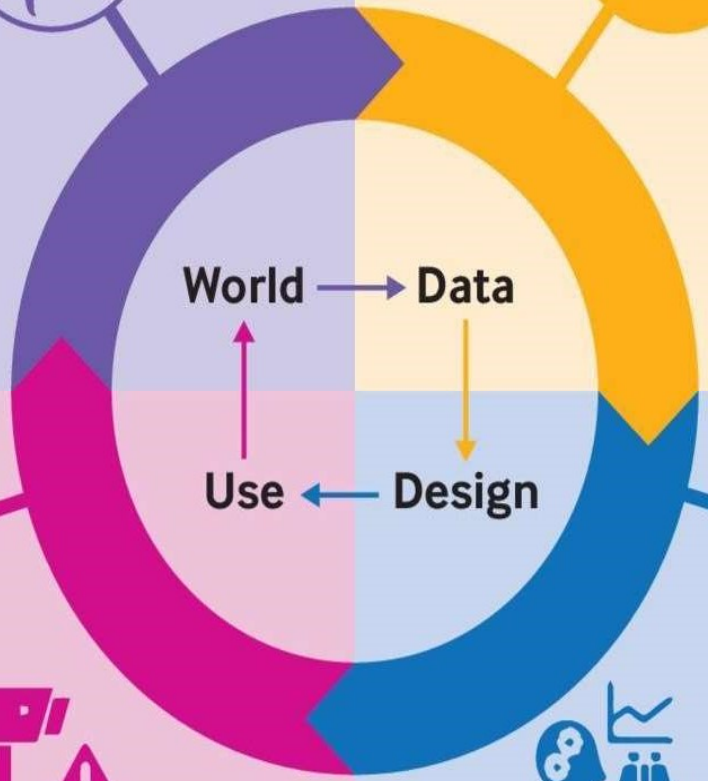
Power imbalances in agenda setting and problem formulation



Biased and exclusionary design, model building and testing practices



Biased deployment, explanation and system monitoring practices






*The only real
disability in life
is a bad attitude*

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