

# Ethical, Legal and Social Implications

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Populations & Communities: Current Practices, Opportunities, and Risks, hosted by the  
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# | Ethical, Legal and Social Implications (ELSI)



## Ethical

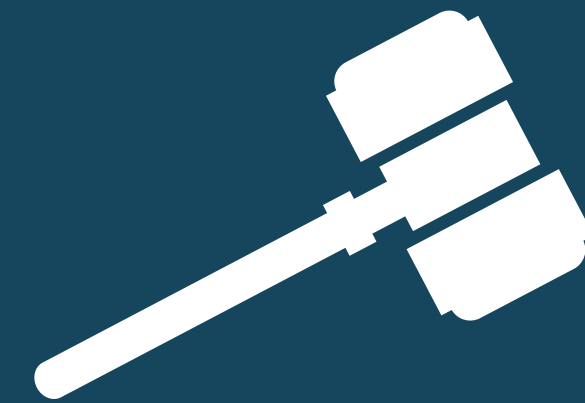
Consent & Literacy

Bystander Rights

Risk of Harm

Benefits to Society

Social Justice



## Legal

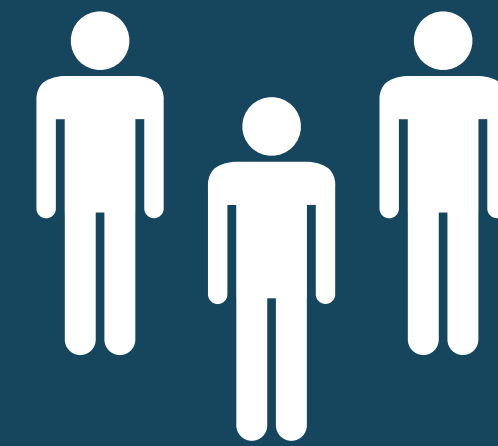
Liability

Privacy: GDPR & CCPR

Intellectual Property

Federal Regs

Conflict of Interest



## Social

Downstream Impact

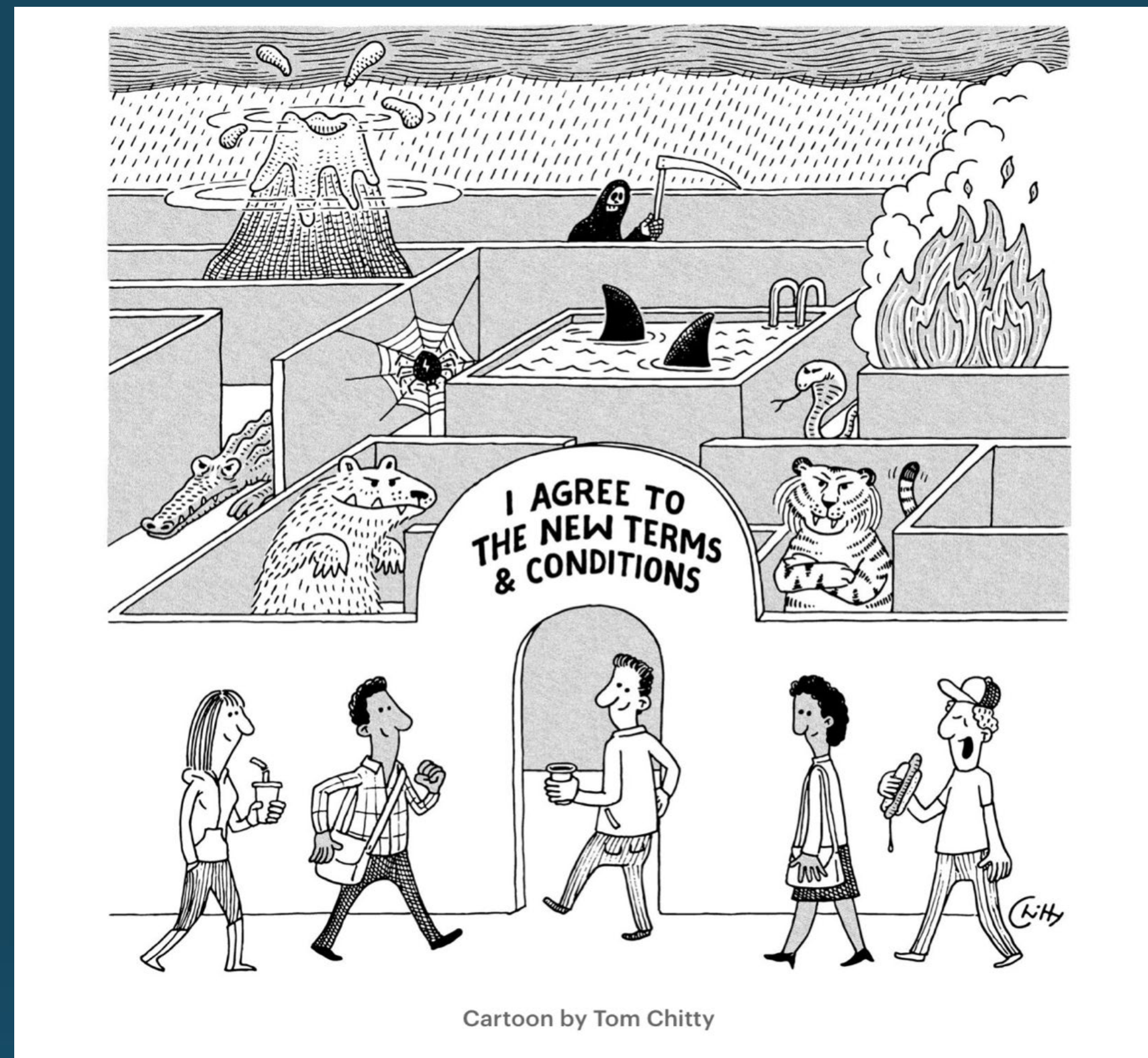
Unknown Unknowns

Sociotechnical Systems

Privacy Expectations

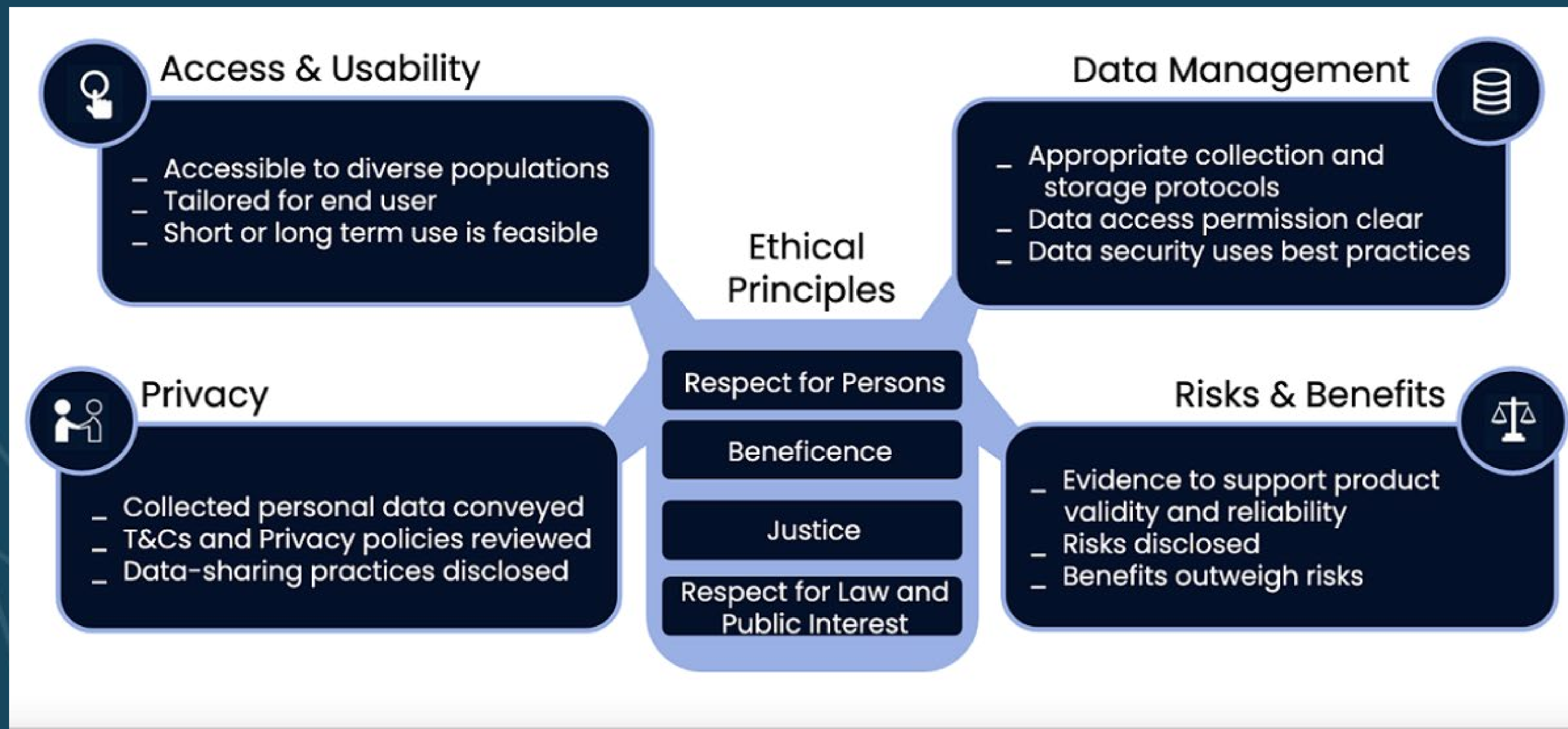
Return of Value

# | Terms and Conditions of Service





# Digital Health Framework | ELSI Decision Support



<https://recode.health/tools>

# | Data Management

Data management includes how data are collected, stored and shared and the extent of incorporation within other systems.

- What is collected?
- What is shared?
- Why is it shared?
- What control does the end-user have?
- Interoperability?

Data Management

Respect for Persons

Beneficence

Contract clearly conveys:

Data collection process?	<input type="checkbox"/>	Data collection by party external to the research team?	<input type="checkbox"/>
Data storage and security?	<input type="checkbox"/>	Potential of data collected on or about a bystander (caregiver?)?	<input type="checkbox"/>
Who will have data access?	<input type="checkbox"/>	Data are accessible to the patient?	<input type="checkbox"/>
Protocols for data sharing?	<input type="checkbox"/>	Data are transferrable to the EHR?	<input type="checkbox"/>
		Data ownership is clear?	<input type="checkbox"/>

Justice

Respect for Law and Public Interest

System vulnerabilities are publicly disclosed?	<input type="checkbox"/>	Data encryption meets expected standards?	<input type="checkbox"/>
Data are not used to target groups or people?	<input type="checkbox"/>	Storage is HIPAA and CFR compliant	<input type="checkbox"/>
		Data are deidentified?	<input type="checkbox"/>



# | Path Forward



Omidyar, 2019

# | Sources

Karen L Celedonia, Marcelo Corrales Compagnucci, Timo Minssen, Michael Lowery Wilson, Legal, ethical, and wider implications of suicide risk detection systems in social media platforms, *Journal of Law and the Biosciences*, Volume 8, Issue 1, January-June 2021, Isab021, <https://doi.org/10.1093/jlb/Isab021>

Nebeker, C., Bartlett Ellis, R.J., Torous, J. Development of a decision-making checklist tool to support technology selection in digital health research, *Translational Behavioral Medicine*, Volume 10, Issue 4, August 2020, Pages 1004–1015, <https://doi.org/10.1093/tbm/ibz074>

Gomes de Andrade, N., Pawson, D., Muriello, D. *et al.* Ethics and Artificial Intelligence: Suicide Prevention on Facebook. *Philos. Technol.* **31**, 669–684 (2018). <https://doi.org/10.1007/s13347-018-0336-0>

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Badal VD, Nebeker C, Shinkawa K, Yamada Y, Rentscher KE, Kim HC, Lee EE. Do Words Matter? Detecting Social Isolation and Loneliness in Older Adults Using Natural Language Processing. *Front Psychiatry*. 2021 Nov 16;12:728732. doi: 10.3389/fpsy.2021.728732. PMID: 34867518; PMCID: PMC8635064.

# Thank You!

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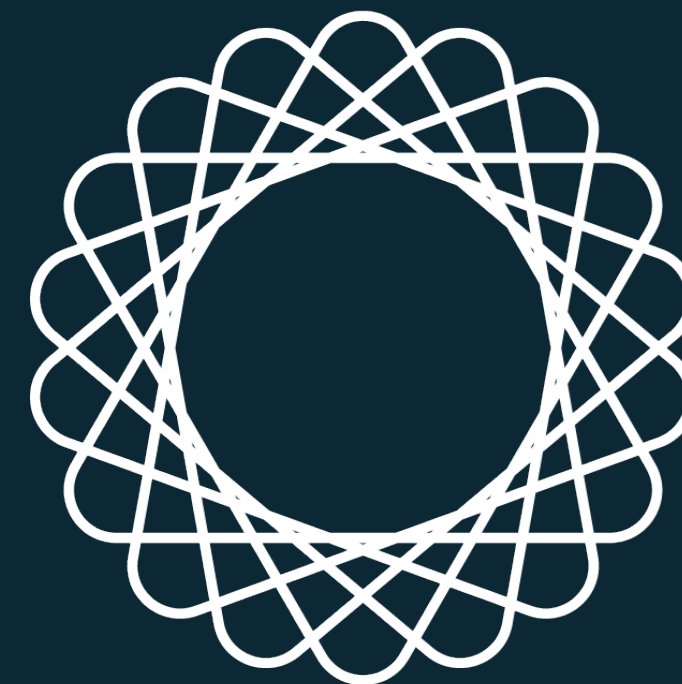
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