

# Spain, August 2022



2 weeks later

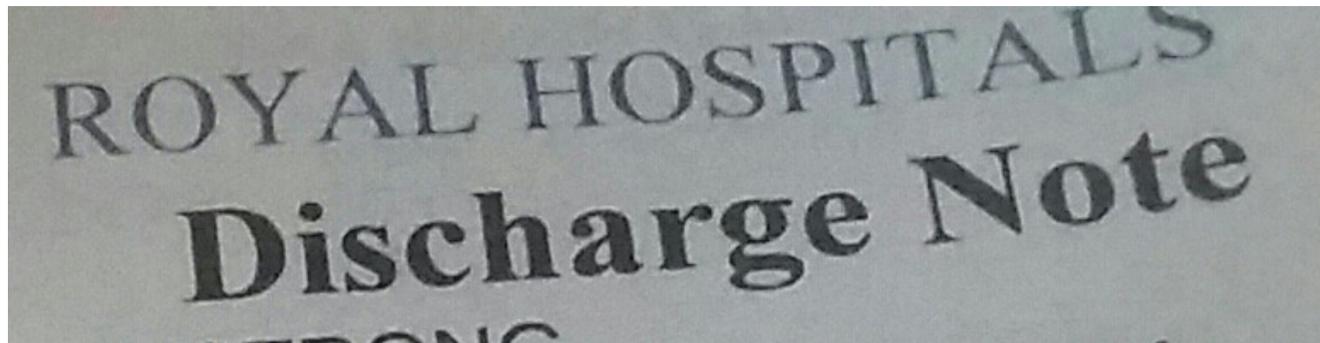


# At the bedside

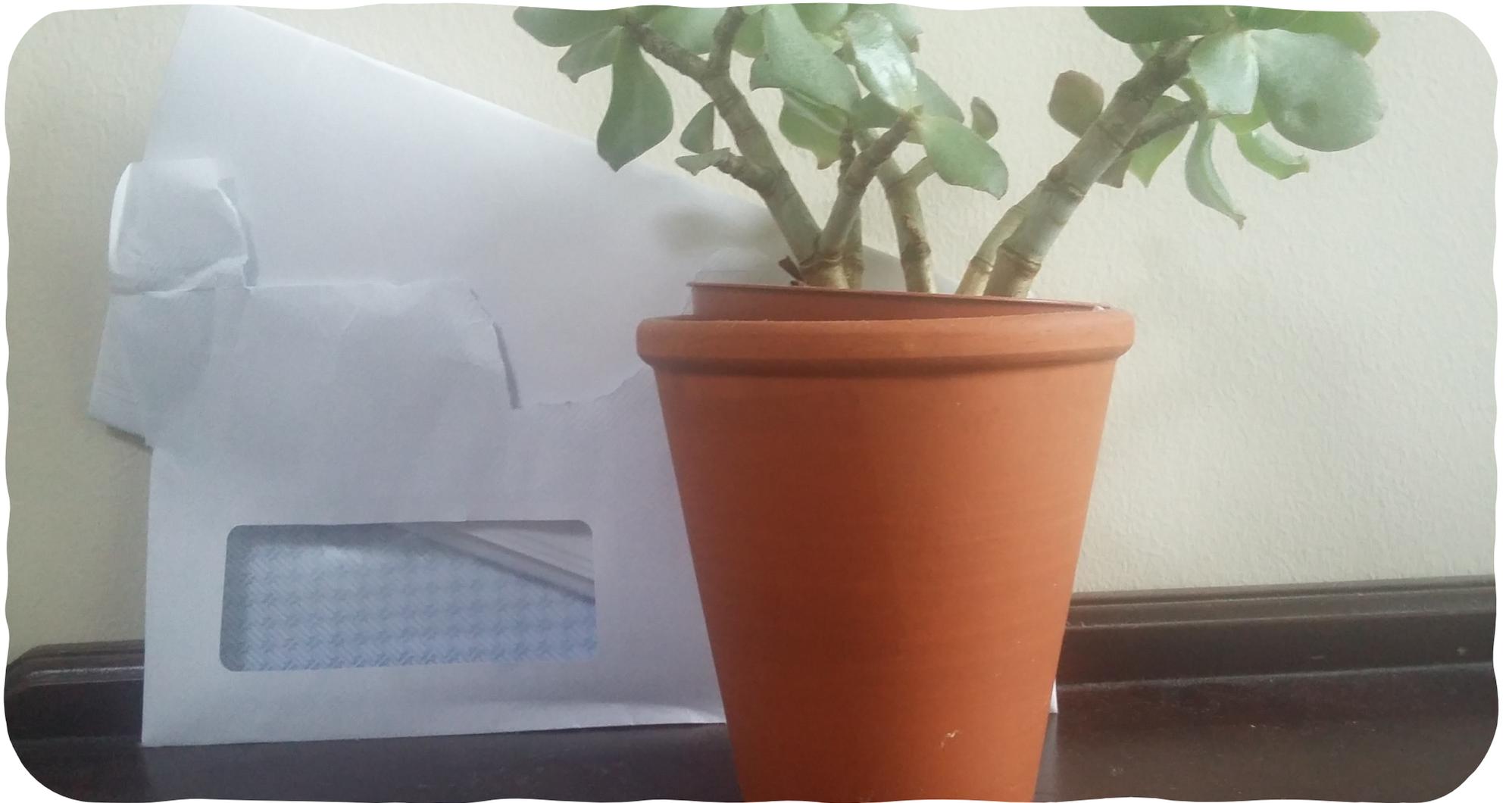
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- Nurse: *“What have you been told?”*
- Doctor: *“CT scans show a thickening.”*





- ***“Very suggestive of tumour”***
- ***“Suggestive of tumour.”***
- ***“? Tumour”***



Leanne

**“There are  
still a lot of  
unknowns.”**





**Consultant: “*It could be a bad thing*”**



**Doctor: “The MRI showed nothing *extra* nasty.”**

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## Summary of Henry's Access

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1. One single hospital discharge letter.
2. No online record access.



**Is online record access**  
**the right thing to do?**

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## Question seems impertinent.

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- Philosophers as gadflies (Socrates) – a person who interferes with the status quo posing potentially upsetting questions, often directed at authorities/received wisdom.
- Goal of deeper understanding.
- Even if the point is to change the world (Marx), you can change it better if you first understand it.



# It's an ethics question.

- Evidence comes in a variety of forms e.g., patient & doctor surveys, objective measures of outcomes, empirical research is hard!
- Ethics organizes this evidence. Mutual relationship.
- The question can't be answered by moral equivalent of foot-stamping.
  - Pixelates the answer: does a disservice to the potential arguments (for/against/neutral).
  - **Principle of charity** requires interpreting arguments in the most rational way possible, considering the best, strongest possible interpretation.
  - Lose the opportunity for deeper understanding.

# Health professional duties

Beauchamp TL, Childress JF  
Principles of medical Ethics.  
Oxford University Press,  
2001

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## **Beneficence**

(promoting health & wellbeing)

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## **Non-maleficence (“do no harm”)**

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## **Patient autonomy**

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## **Trust, confidentiality, privacy**

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## **Justice**

No access

Letter

Online

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**Beneficence**

(promoting health & wellbeing)

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**Non-maleficence**

("do no harm")

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**Patient autonomy**

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**Trust, confidentiality/privacy**

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**Justice**

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# Henry's case

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# Beneficence (health & wellbeing)

	No access	Letter	Online access
	⊖	⊖	?

## ➤ Could potentially have benefited Henry's health?

- Neves, A.L., et al., 2020. Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis. *BMJ quality & safety*, 29(12), pp.1019-1032;
- Liu, P.L., Zhao, X. and Ye, J.F., 2022. The Effects of the Use of Patient-Accessible Electronic Health Record Portals on Cancer Survivors' Health Outcomes: Cross-sectional Survey Study. *Journal of Medical Internet Research*, 24(10), p.e39614.

# Non-maleficence ('do no harm')

	No access	Letter	Online access
			

- Without access, unidentified errors in records might have caused harm.
- Existential anxiety isn't the provenance of the doctor. Rexhepi H, Ahlfeldt R-M, Cajander A, *et al.* Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study. *Health Informatics Journal* 2018;**24**:115–24.
- **Doctrine of Double Effect**: Something morally good that has a morally bad side effect is tolerable if this effect is proportional to the good.

# Non-maleficence ('do no harm')

	No access	Letter	Online access
			

- Preventable anxiety & delayed information (“scanxiety”).
- Nocebo effects: anticipation of side effects can increase them
  - Blease, C., 2022. Sharing online clinical notes with patients: implications for nocebo effects and health equity. *Journal of Medical Ethics*.

# Non-maleficence ('do no harm')

	No access	Letter	Online access
			

➤ If Henry's doctors **'dumbed' down** the records with the knowledge he might read them, there is potential for this to lead to harm.

- Blease, C., Torous, J. and Hägglund, M., 2020. Does patient access to clinical notes change documentation?. *Frontiers in Public Health*, 8, p.577896.
- DesRoches, C.M., et al 2020. The views and experiences of clinicians sharing medical record notes with patients. *JAMA Network Open*, 3(3), pp.e201753-e201753.

# Respect for patient autonomy

	No access	Letter	Online access
			

- Respect for autonomy embeds the right to self-determination in medical decisions; necessary for informed consent.
- Components: capacity; communication of medical information is clear; adequate timely disclosure of relevant information; conditions for voluntariness.
- Understood as “**respectful action**, not merely a respectful *attitude*” (Beauchamp & Childress, 2008)

## Respect for patient autonomy (cont'd)

	No access	Letter	Online access
			

- Data ≠ Information ≠ Knowledge.
- **Relational construct**: it is enriched by social relationships & these can foster or impede processes of reflection, deliberation, and authentic decision-making. – **Leanne; Internet resources; Social media.**
- Understanding ≠ not freedom from confusion ('higher state of confusion').
- In the letter doctors were confused – with help we shared in that confusion.

# Trust

	No access	Letter	Online access
			

- Henry reliant on doctor's faltering face-to-face communication.
- Reciprocity builds trust:
  - Bell, S.K et al 2021. Tackling ambulatory safety risks through patient engagement: what 10,000 patients and families say about safety-related knowledge, behaviors, and attitudes after reading visit notes. *Journal of Patient Safety*, 17(8), pp.e791-e799.

# Confidentiality / Privacy

	No access	Letter	Online access
			

- Henry's letter was found and read.
- Information typed into Google; Advertisements for **spousal grief**.
  - Zuboff, S., 2019. *The age of **surveillance capitalism***: Profile books.
  - Cohen, I.G. and Mello, M.M., 2018. HIPAA and protecting health information in the 21st century. *Jama*, 320(3), pp.231-232.

# Justice

	No access	Letter	Online access
Negative stereotyping			

- Henry's capacity to understand was discredited ('epistemic injustice')
- Blease, et al 2022. Patients, clinicians and open notes: information blocking as a case of epistemic injustice. *Journal of Medical Ethics*, 48(10), pp.785-793.

# Justice

	No access	Letter	Online access
Distribution of information/ knowledge			

- Henry benefited from **educational attainment** (literacy & digital literacy)
- Henry benefited from **social capital**: i.e., Leanne.
- Henry *would have* benefited by **capital** (internet & device access).
  - Rodriguez, J.A.,2020. Association between patient portal use and broadband access: a national evaluation. *Journal of General Internal Medicine*, 35(12), pp.3719-3720.

No access

Letter

Online

**Beneficence**

(promoting health & wellbeing)



**Non-maleficence**

("do no harm")



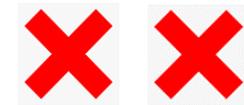
**Patient autonomy**



**Trust, confidentiality/privacy**



**Justice**



# Conclusions

- The perfect is the enemy of the good
- On balance access for Henry would have been the right thing to do.
- The 'right' thing is nuanced; must be indexed to the ethical norm in question, informed by evidence.
- Ethical dilemmas aren't immutable: this is not a rigid ledger.
- Resolving dilemmas will require imaginative problem-solving and intention.

# Ethical issues: now and in the future

- **Autonomy**: Transparency doesn't equate with understanding: data vs information vs knowledge – records should support understanding via design features.
- **Privacy**: epoch of the internet – our health data is gathered & curated by for-profit entities. Challenges with GDPR. Google ≠ Encyclopedia Britannica
- **Harms**: Dumbing down records; clinicians' pre-emptive perceptions of patients' anxieties lead to real harm?
- **Harms; Autonomy; Trust**: Special patient populations: adolescents, elder care, serious mental illness, minorities, people who are vulnerable to negative stereotyping.

Tack för att  
du lyssnade  
och grattis på  
10-årsdagen!

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