

*Patient Empowerment  
or  
Information Overload:  
an international perspective on giving patients  
real-time access to their medical notes.*

Dr Zoë Fritz  
University of Cambridge  
Consultant Physician; Wellcome Fellow in Ethics and Society  
Contact: [zoeffritz@gmail.com](mailto:zoeffritz@gmail.com)

- 
- ▶ Provoke debate about the ethical impacts of sharing medical records
  - ▶ Propose methods for evaluating the impact of sharing medical records.

# What is the role of the medical record?

- ▶ A narrative record of what has happened /collection of results- objective
- ▶ A 'working document' of Physicians' thinking, discussions, opinions - subjective
- ▶ A training document

# All of them!

- ▶ But not **designed** to do all of them...
- ▶ A document which has reactively developed rather than being designed.
- ▶ Developed in response to the **needs of clinicians'** rather than the **needs of the patient**

So what are the needs of the patient?

# Needs of patient

- ▶ ? To be informed about about what is happening
- ▶ ? To inform their relatives with accurate information
- ▶ ? To be empowered to ask questions
- ▶ ? To contribute to decision-making
- ▶ ? To be able to have informed trust in their doctors
- ▶ ? To contribute to their own care?

# Patient access to records... the needs have changed

- ▶ 200 years ago (1820): only 50% of Danes could read and write
- ▶ 100 years ago (1920): very few effective medications
- ▶ 50 years ago (1970): very little evidence base for 'best' treatment
- ▶ 50 years ago (1970): Beauchamp and Childress 'four principles'
- ▶ 25 years ago (1995): the (beginning of) the ascendancy of patient autonomy

# So... a "no brainer"?

- ▶ In the context of
  - ▶ An evidence base of effective interventions
- ...and
  - ▶ A literate, engaged population
- ▶ We should **all share all records in 'real time'**?

# What is known?

- ▶ For specific diseases (e.g. diabetes, COPD)
  - ▶ helps self management
- ▶ For specific times of life (e.g. maternity records)
  - ▶ helps give control, improves communications
- ▶ For specific settings (e.g. outpatients)
  - ▶ quite a lot of work has been done...
  - ▶ Most extensive is 'OpenNotes' by Tony Delbanco's team

# OpenNotes

## ▶ **Increases Patient Empowerment**

- ▶ Delbanco, T., et al. (2012).
  - ▶ 77% to 59% [corrected] across the 3 sites reported that open notes helped them feel more in control of their care;
  - ▶ 60% to 78% of those taking medications reported increased medication adherence;

## ▶ **Improves Patient Safety**

- ▶ Bell, S. K., et al. (2017).
  - ▶ 7% (331) of patients reported contacting their doctor's office about their note.
  - ▶ Of these, 29% perceived an error, and 85% were satisfied with its resolution.

## ▶ **Does not increase number of visits:**

- ▶ Leveille, S. G., et al. (2016)

# “Portals”

- ▶ An electronic route to **targeted** parts of the medical record (e.g. blood results, medication lists, etc.) is becoming more common.
- ▶ Several systematic reviews on the design, use and impact of such portals have been conducted.
  - ▶ Goldzweig, C. L., et al. (2013).
  - ▶ Prey, J. E., et al. (2014).
  - ▶ Kelly, M. M., et al. (2017).

# Portals - the evidence

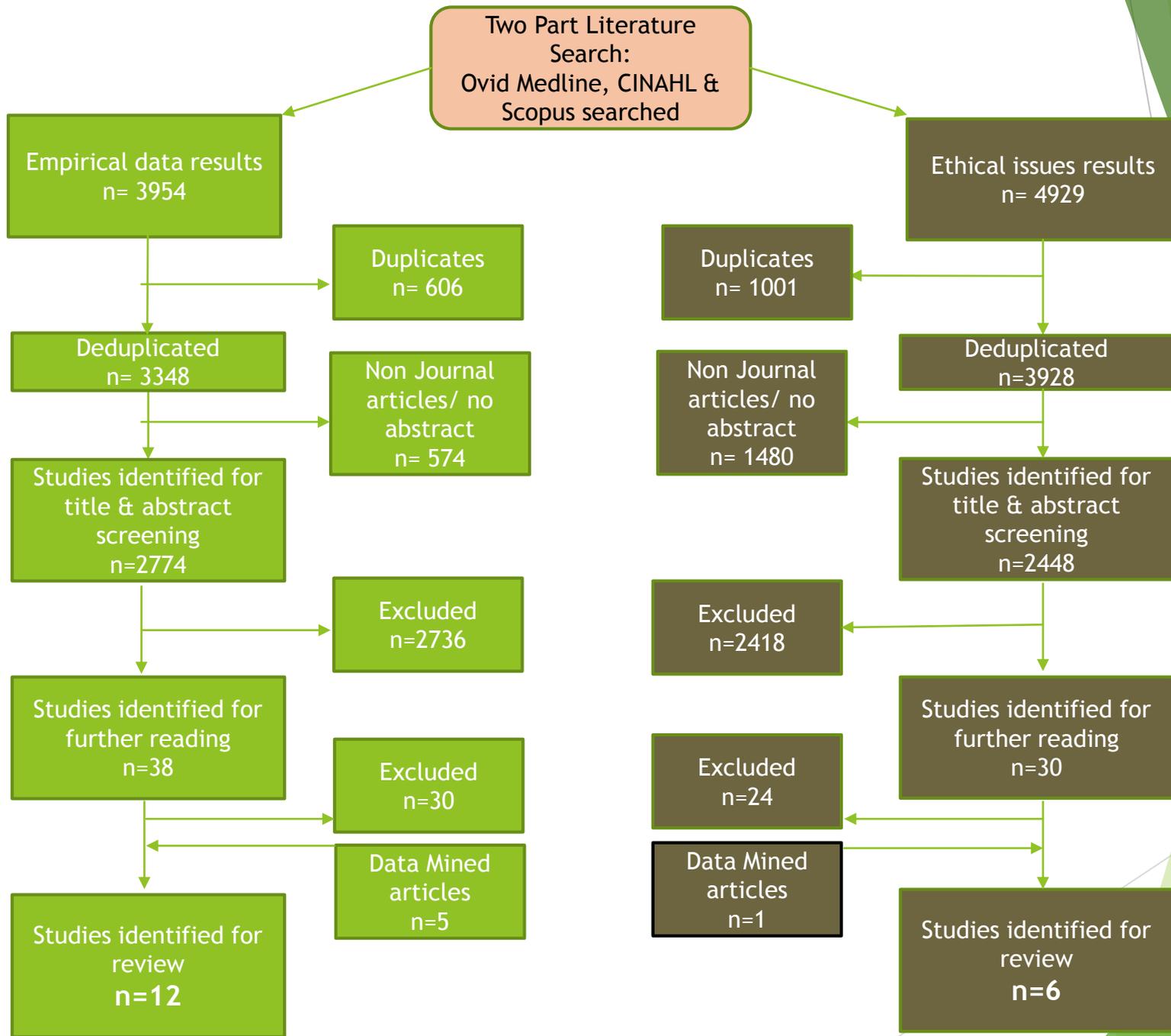
- ▶ Patients are generally **enthusiastic** about the possibility of accessibility
- ▶ Positive or neutral health outcomes were observed
  - ▶ **Improved communication**
  - ▶ Possibility to spot **errors**
- ▶ However, clinician contact for portal users increased
  - ▶ **disparity of uptake** among different ethnic and socioeconomic groups was noted.

# What questions did we have?

- ▶ 1) What studies have there been of sharing records with medical patients in the **in-patient** setting, and in particular on the impact on **trust** and **communication** between patients and doctors?
- ▶ 2) What are the ethical issues associated with sharing records with medical patients?

# Our Review

- ▶ Two literature searches, on the Medline, CINAHL and Scopus databases were conducted, for:
  - ▶ (1) hospitalised patients, patient access to records and its effects on communication and trust within the doctor-patient relationship; and
  - ▶ (2) patient access to records and ethical implications)
- ▶ A critical interpretive synthesis was conducted
- ▶ Stephanie D'Costa ( a medical student) and Isla Kuhn ( a librarian) co-authors



Integrated and analysed evidence  
to ask:

**“What are the ethical issues with  
sharing the medical record in the  
acute setting?”**

# Impact on Patient care -1

- ▶ **Empowered patients by**
  - ▶ improving **trust and knowledge** (O'Leary *et al.* 2016)
  - ▶ facilitating patients to work *with* doctors.  
(Grossman *et al* 2017; Collins *et al.* 2017)
  - ▶ enabling patients to **correct inaccuracies**  
(Gilhooly and McGhee 1991, Wibe *et al.* 2011)

# Impact on Patient care -2

- ▶ But...would patients **feel responsible** if something was missed:(Wibe *et al.* 2010, Davis and Smith 2016)
  - ▶ “*patients could end up feeling they are to blame for their own poor outcomes*”(Davis and Smith 2016)
- ▶ Concern that written comms might supplant face-to-face(Dykes, *et al.* 2013)
  - ▶ did not happen in the only study to trial giving patients a written daily summary (Weinert 2017)

# Conflict between patient and physician perspectives - 1

- ▶ Doctors concerned access to notes will **overwhelm or unnecessarily worry** patients, (Wilcox 2010, Weinert 2017)
  - ▶ Patients were reassured by the shared information. (Wibe and Slaughter 2009)

# Examples of potentially anxiety producing information:

- ▶ *“potentially alarming information that carries a low degree of certainty such as a cancer on a differential diagnosis list”*(Grossman 2017)
- ▶ Lab (and other) results in real time
  - ▶ patients strongly supported this
  - ▶ doctors preferred a delay, in part so they could interpret them appropriately, offer support and create a future healthcare plan. (Wilcox 2010, Beard 2012, O'Leary 2016)
  - ▶ *“one of the primary duties of a physician is not only to alert the patient to abnormal results but also to education them on their condition and appraise them of the follow up that will be needed”*. (Davis and Smith 2016)

# Conflict between patient and physician perspectives -2

- ▶ Debate about whether patients should be co-creators of notes:
  - ▶ Doctors were concerned that patients editing their own record might make them less reliable. (Spriggs, Arnold et al. 2012, Gu, Orr et al. 2013)

# Potential increase in disparity of Health care

- ▶ Those from lower socioeconomic groups less likely to engage despite an often greater need
  - ▶ “[to]what extent should less engaged individuals be punished for their ignorance” (Spriggs 2012)
  - ▶ “There is an ethical imperative to work to reduce the potential for the emergence or amplification of health disparities with respect to portal use” (Lyles 2017)

# What research questions remain?

- ▶ What do **patients** want?
- ▶ What is **changed** in the medical record when it is made accessible?
- ▶ Are there *actual* or only *hypothetical* increases in the discrepancy in health care that is given?
- ▶ What impact does it have on **training**?
- ▶ Are there any *actual* harms to patients (e.g. in causing anxiety) or only *hypothetical*?
- ▶ What about a summary record?

# We set out to answer one of these...

- ▶ What do patients want? ( in the UK!)
- ▶ Mixed Methods study:
  - ▶ semi-structured interviews with 12 patients and 13 physicians, transcribed them, coded and analysed them.
  - ▶ Likert-scale and free-text validated questionnaire survey of physicians (32) and patients (248) from acute medical units in two hospitals.
  - ▶ Collaborators Alex Schlindwein and Anne-Marie Slowther

# Findings -1

- ▶ **Current approach of verbal information not good enough**
  - ▶ 27% left without knowing their diagnosis.
- ▶ **Openness and honesty** were seen as the primary contributor to building trust
- ▶ 81% of patients supported the idea of having access to the full medical record
  - ▶ for empowerment;
  - ▶ the right to information about oneself;
  - ▶ as an *aid memoire* for discussion

# Findings - 2

- ▶ Concerns were expressed that it might induce **anxiety** in patients, and **change the nature of what was written** in the medical notes:
- ▶ Physicians reported that there were things which they often did not tell patients immediately (or at all):
  - ▶ mildly abnormal blood results;
  - ▶ the unlikely but serious cause for symptoms requiring further (non-invasive) investigation;
  - ▶ the suspicion that the cause of their symptoms was somatisation.

Explicit Ethical issues raised

# Whose responsibility is it?

*While withholding information from patients may initially be perceived as paternalistic behaviour, it can also be seen as part of a clinician's responsibility, both to the individual patient and to the system.*

# Discretionary judgement of disclosure

- ▶ Working out *what* information to give and *when* in order to minimise psychological harm to each patient
  - ▶ important for the **therapeutic relationship**
  - ▶ and important to avoid devoting resource (in time explaining things that would ultimately not be relevant to that patient's care) which might be better deployed elsewhere.

# A moral good?

*Is there a moral good in taking on some of the 'emotional work' of considering uncertainty and risk which balances the negative paternalistic concerns?*

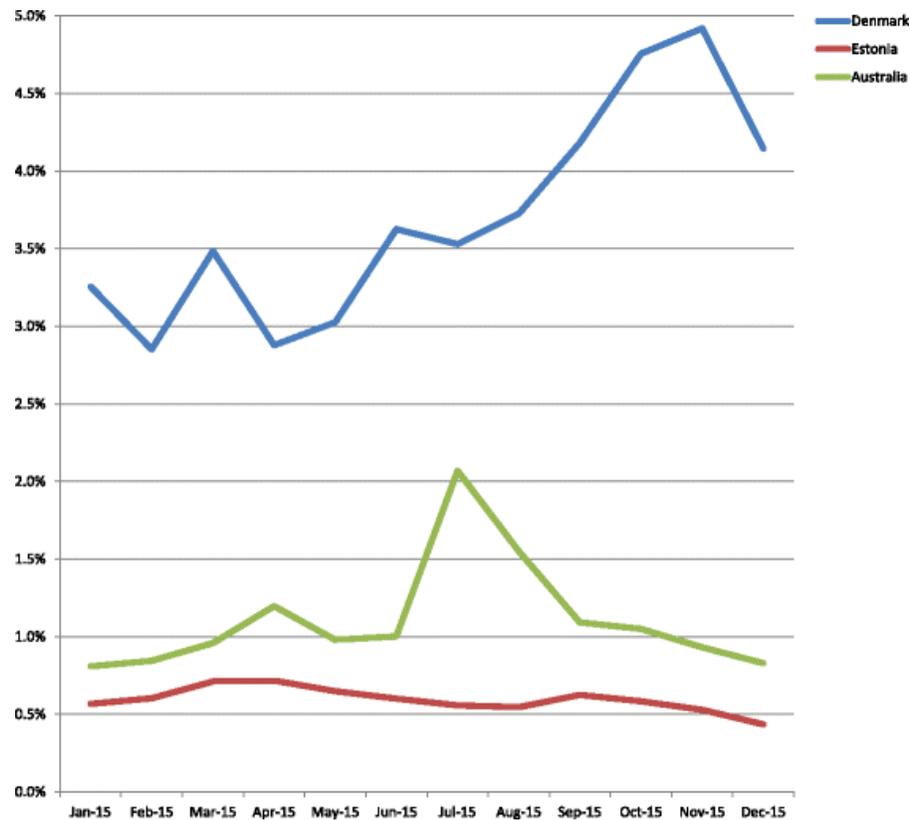
Pragmatic approach:

“Patient’s want it and it’s the right thing to do”

# Where has it been introduced nationally?

- ▶ Countries which plan (or already do) provide citizen access to health data
- ▶ **Australia, Canada, Denmark, Estonia, Finland, France, Iceland, New Zealand, Norway, Scotland, Singapore, and Sweden,**
  - ▶ Nohr, C., et al. (2017). "Nationwide citizen access to their health data: analysing and comparing experiences in Denmark, Estonia and Australia." BMC Health Serv Res 17(1): 534.

# A summary comparison of login data by citizens in Denmark, Australia and Estonia during 2015.



Taken from: Nohr, C., et al. (2017).

# Denmark leading the world!

- ▶ So what can the world learn from Denmark....?

# Research questions remaining...

- ▶ What do patients want?
- ▶ What is changed in the medical record?
- ▶ Are there *actual* or only *hypothetical* increases in the discrepancy in health care that is given?
- ▶ What impact does it have on training?
- ▶ Are there any *actual* harms to patients or only *hypothetical* ones?

# How can we find out what happened in Denmark?

- ▶ Retrospective case note analysis
  - ▶ E.g. 100 consecutive patients with a diagnosis of myeloma before and after patient access to notes
- ▶ Review of Patient involvement in error reporting
- ▶ Qualitative work
- ▶ Questionnaires
- ▶ Review of Hospitals' working patterns

- ▶ Good to respect the patient right to information
- ▶ Important to think about unintended consequences
  - ▶ Should we change the medical record so that it is designed for its new purpose?
- ▶ Denmark can teach the world!
  - ▶ (but you already knew that!)

# Thank you...

- ▶ Stephanie D'Costa
- ▶ Alex Schlindwein
- ▶ Anne Marie-Slowther
- ▶ Isla Kuhn
- ▶ All the patients and physicians who participated in the questionnaire
- ▶ The Wellcome Trust

# References 1

Beard L, *et al* The challenges in making electronic health records accessible to patients. *J Am Med Inform Assoc.* 2012;19(1):116-20.

Bell, S. K., et al. (2017). "When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient-doctor relationship." *BMJ Qual Saf* 26(4): 262-270.

Collins SA, *et al* Acute care patient portals: a qualitative study of stakeholder perspectives on current practices. *J Am Med Inform Assoc.* 2017;24(e1):e9-e17.

Davis KA, Smith LB. Ethical Considerations about EHR-Mediated Results Disclosure and Pathology Information Presented via Patient Portals. *AMA Journal of Ethics.* 2016;18(8):826-

Delbanco, T., et al. (2012). "Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead." *Annals of internal medicine* 157(7): 461-470.

Dijkstra RF, , et al. Introduction of diabetes passports involving both patients and professionals to improve

Dykes PC, *et al* Participatory Design and Development of a Patient-centered Toolkit to Engage Hospitalized Patients and Care Partners in their Plan of Care. *AMIA Annu Symp Proc.* 2014;2014:486-95.

Dykes PC, *et al* Building and testing a patient-centric electronic bedside communication center. *J Gerontol Nurs.* 2013;39(1):15-9.

Elbourne D, *et al* The Newbury Maternity Care Study: a randomized controlled trial to assess a policy of women holding their own obstetric records. *Br J Obstet Gynaecol.* 1987;94(7):612-9.

Ferreira A, et al. Why facilitate patient access to medical records. *Stud Health Technol Inform.* 2007;127:77-90.

Gilhooly ML, McGhee SM. Medical records: practicalities and principles of patient possession. *J Med Ethics.* 1991;17(3):138-43.

# References 2

Goldzweig CL, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann Intern Med.* 2013;159(10):677-87.

Grossman LV, et al. Implementation of acute care patient portals: recommendations on utility and use from six early adopters. *Journal of the American Medical Informatics Association.* 2017;04:04.

Gu Y, et al. Why a shared care record is an official medical record. *N Z Med J.* 2013;126(1384):109-17.

Kelly MM, et al. Inpatient Portals for Hospitalized Patients and Caregivers: A Systematic Review. *Journal of Hospital Medicine.* 2017;20:20.

Lee EH, et al. Patient-centric medical notes: Identifying areas for improvement in the age of open medical records. *Patient Education and Counseling.* 2017;100(8):1608-11.

Leveille, S. G., et al. (2016). "Do Patients Who Access Clinical Information on Patient Internet Portals Have More Primary Care Visits?" *Med Care* 54(1): 17-23.

Lyles CR, et al. Legal, Practical, and Ethical Considerations for Making Online Patient Portals Accessible for All. *Am J Public Health.* 2017;107(10):1608-11.

O'Leary KJ, et al. The effect of tablet computers with a mobile patient portal application on hospitalized patients' knowledge and activation. *J Am Med Inform Assoc.* 2016;23(1):159-65.

Prey JE, et al. Patient engagement in the inpatient setting: a systematic review. *J Am Med Inform Assoc.* 2014;21(4):742-50.

Ross SE, Lin CT. The effects of promoting patient access to medical records: a review. *J Am Med Inform Assoc.* 2003;10(2):129-38.

Spriggs M, et al. Ethical questions must be considered for electronic health records. *J Med Ethics.* 2012;38(9):535-9.

# References 3

Urowitz S, *et al* . Is Canada ready for patient accessible electronic health records? A national scan. *BMC Medical Informatics & Decision Making*. 2008;8:33.

Vawdrey DK, *et al* A tablet computer application for patients to participate in their hospital care. *AMIA Annu Symp Proc*. 2011;2011:1428-35.

Weinert C. Giving Doctors' Daily Progress Notes to Hospitalized Patients and Families to Improve Patient Experience. *Am J Med Qual*. 2017;32(1):58-65.

Weiss M. For doctors' eyes only: medical records in two Israeli hospitals. *Culture, Medicine & Psychiatry*. 1997;21(3):283-302.

Wibe T, *et al* Why do people want a paper copy of their electronic patient record? *Stud Health Technol Inform*. 2010;160(Pt 1):676-80.

Wibe T, *et al* Lay people's experiences with reading their medical record. *Soc Sci Med*. 2011;72(9):1570-3.

Wibe T, Slaughter L. Patients reading their health records - what emotional factors are involved? *Studies in Health Technology & Informatics*. 2009;146:174-8.

Wilcox LG, *et al* Physician Attitudes about Patient-Facing Information Displays at an Urban Emergency Department. *AMIA Annu Symp Proc*. 2010;2010:887-91.