

“Privacy at What Cost? Using Electronic Medical Records to Recover Lapsed Patients Into HIV Care”

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Paper studies impact of EMR adoption on HIV treatment in 106 health clinics in Malawi between 2007 and 2019

Finds significant health gains from EMRs

- EMR adoption at a clinic is followed by significant increases in ART patients in care and decreases in ART patient deaths
- ART patients in care increase immediately in adoption year
 - Increase is from returning patients, new patients decline
- Deaths decrease with lag overall –
 - Immediately for young children, but offset by increase in deaths for 50+
- Event study on deaths shows no pre-trends before adoption
 - Not possible for patients in care because only 1 year of pre-adoption data

Finds conflict between privacy and health

- The health benefits of EMRs are from tracing patients who starts ART treatment and encouraging them to return after missing a visit
- Patients can give/withhold consent to this tracing.
 - Tracing is not directly about sharing information, but about uses that could lead to disclosure – i.e., if clinic staff visit the home or elicit help from community leaders.
- No beneficial impact of EMRs on patients who provided affirmative consent, but large benefits for those who did not
- Possible because clinics still traced those patients!
- Implication is that honoring privacy preferences would have lowered follow-up care and increased mortality

Great, great, great

- Great topic
- Great setting
- Great results

- Terrific and interesting and challenging paper

Comments

- Want to know more about consent rules and selection into consent
- Two small thoughts on mechanism and quality of care
- Request for estimates from a model that includes zeros as zeros
- Draw connections with my work with Catherine Tucker on health privacy

Want to know more about consent decision

- Great majority of non-consenting were not asked for consent “NA”
- What is the source of the consent policy? Is it law or a clinic guideline? Is it new? Is it enforceable? Could consent be added or rescinded after the initial visit? Could you allow some tracing (phone calls) but not others (banishment threats from the chief)
- People who did not provide consent, including with “no” responses were still traced after EMRs. They didn’t complain or sue?
- Prior to EMRs, tracing was rare/difficult, but the question was still asked.
- What did people expect when deciding on consent? Did that change?

Lack of enforcement

- Asking for consent to trace and never tracing is not a problem as much as asking and ignoring the information
- The paper presents the arguments from public health for ignoring the consent/privacy preferences, but not for eliciting and violating them
- This is a violation of patient trust
- I would be worried about people engaging in other behaviors to protect their privacy, once they learn about the tracing
- This could be not providing their names or contact information or even avoiding testing or initiating treatment – particularly concerning if the patient (or their guardian) doesn't want to follow treatment
 - Is the decline in new patients a source of concern?

Who are the “non-consenting” people?

- Larger benefits for non-consenting group goes against standard Roy model (e.g., people who want to be traced because they have trouble remembering but want care)
- Patients who provide consent are less likely to miss an appointment or lapse in care and less likely (pre-EMR) to die than those who refuse
- Although non-consent can be described as opting for more privacy, not clear that the source is valuing privacy more
 - Could be value health less, trust the clinic staff less, or have worse phone access.
- Increase in care is similar between “no” and “NA” (though mortality drops happen sooner for “no”; possibly because they had more advanced HIV) – surprising because most people consented when asked

Mechanism: value of linking information?

- Paper argues that value of EMR on health is from increasing rate of continuing/resuming ART care for existing patients
- Also notes (in discussion of declining new patients) that EMRs (possibly interacted with health passports) improve matching of patient records across visits
- This helps tracing.
- Does it also have a direct benefit in quality of care? Does the optimal dosage/therapy depend on medical history?

Question about non-results for TB

- Paper finds only small insignificant increase in TB diagnosis and treatment in first year after EMR adoption
- Interprets this as lack of an impact of the EMR on TB care
- But I think that assumes that TB rates are unchanged. Why?

ART also has a substantial effect on prevention of HIV-associated tuberculosis. Studies have shown that ART reduces the risk of tuberculosis by 80-92% [15-17]. Moreover, recent data indicates that ART reduces the risk of TB by 50% in people with a CD4 > 350 [18].

https://www.who.int/hiv/topics/tb/faq_art_prevention_hiv_and_tb_revised_april_2011.pdf

Estimation request on functional form

- Would be nice to estimate a model that includes zeros and treats them as such – adding 1 to log or using IHS transformation keep zeros in ad hoc way
- If concern is that clinics serve larger/smaller population bases, could scale patients and deaths to the local/catchment area population
 - Deaths could (should?) be scaled to total patient population (including lapsed)
- My guess is that zeros are rare for full sample outcomes, but could be more common on subgroups

Comparison to “Can Health IT Save Babies?”

- Tension between privacy and life-saving EMR is common feature of current paper and Miller and Tucker (2011), which finds lower infant mortality after US hospitals adopt EMRs
- Common to both papers is the focus on settings where improved accessibility of patient data is the key mechanism of benefit from IT. Timeliness was key in maternity care; here it is a simple search operation. Neither are doing complex prediction or analysis.
- Difference in institutions -- Here, the lack of enforcement of privacy protections is what enables benefits from tracing. In *Babies*, enforceable privacy regulation for patient data slows EMR adoption.

Comparison to “Privacy Protection, Personalized Medicine, and Genetic Testing”

- Miller and Tucker (2018) study impact of different types of genetic privacy regulation on rates of genetic testing for cancer risks.
- Similar to this paper, we identify a subset of the population with strong tastes for privacy shown by their behaviors
- Refusing to answer questions about HIV status in the survey or not providing their complete name when receiving an HIV test
- We find significantly larger impacts of privacy regulation on their behavior
- Connection with privacy of child information on HIV status here and genetic information in our paper because both potential to reveal information about health status of family members as well

Thanks