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Alternatively, these funds could be reallocated to global trials with the ability to question widely accepted beliefs. A single randomised trial of primary tumour resection (vs no resection) in metastatic breast cancer, which found no survival benefit (HR 1·04, 95% CI 0·81–1·34; p=0·79), was able to answer an important clinical question, and prevented women from having an unnecessary and disfiguring surgery.

Drug repurposing is well intentioned and appealing. However, available evidence suggests caution should be taken. Enthusiasm for these drugs has been driven by findings from retrospective observational studies that are subject to bias. After the application of rigorous methods (causal observational design and randomised trials), no benefits were observed. Many frequently discussed repurposed drugs lack activity—the ability to shrink tumours—a well-established prerequisite for selecting drugs to advance to randomised trials. Alternatives exist, which achieve the same goals as those of repurposing, but constitute a better use of resources. For these reasons, we believe drug repurposing is a well-intentioned but misquided approach.

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- 1 Cousins S. Repurposing drugs to fight cancer. Feb 25, 2020. https://www. nytimes.com/2020/02/25/opinion/repurposing-drugs-cancer.html (accessed Feb 26, 2020).
- Moertel CG, Fleming TR, Rubin J, et al. A clinical trial of amygdalin (laetrile) in the treatment of human cancer. N Engl J Med 1982; 306: 201–06.
- 3 Lerner IJ. Laetrile: a lesson in cancer quackery. CA Cancer J Clin 1981; 31: 91-95.
- 4 Gyawali B, Prasad V. Drugs that lack single-agent activity: are they worth pursuing in combination? *Nat Rev Clin Oncol* 2017; **14**: 193–94.
- 5 Nielsen SF, Nordestgaard BG, Bojesen SE. Statin use and reduced cancer-related mortality. N Engl J Med 2012; 367: 1792–802.
- 6 Emilsson L, García-Albéniz X, Logan RW, Caniglia EC, Kalager M, Hernán MA. Examining bias in studies of statin treatment and survival in patients with cancer. JAMA Oncol 2018; 4: 63–70.
- 7 Seckl MJ, Ottensmeier CH, Cullen M, et al. Multicenter, phase III, randomized, double-blind, placebo-controlled trial of pravastatin added to first-line standard chemotherapy in small-cell lung cancer (LUNGSTAR). J Clin Oncol 2017; 35: 1506–14.
- Chen L, Zhou W, Hu X, Yi M, Ye C, Yao G. Short-duration versus 1-year adjuvant trastuzumab in early HER2 positive breast cancer: a meta-analysis of randomized controlled trials. Cancer Treat Rev 2019; 75: 12–19.
- 9 Helwick C. Trastuzumab for 9 weeks fails to show noninferiority in HER2-positive breast cancer. Feb 10, 2018. https://www.ascopost.com/ issues/february-10-2018/trastuzumab-for-9-weeks-fails-to-shownoninferiority-in-her2-positive-breast-cancer/ (accessed March 6, 2020).
- 10 Badwe R, Hawaldar R, Nair N, et al. Locoregional treatment versus no treatment of the primary tumour in metastatic breast cancer: an open-label randomised controlled trial. *Lancet Oncol* 2015; 16: 1380–88.



## Open notes in cancer care: coming soon to patients



COVID-19 has disrupted care for people with cancer.1 Postponed treatments, physical distancing, and the vulnerabilities of infection compound the stress and uncertainties already felt by patients and their carers, as they are learning to negotiate the move to telemedicine. By telephone or video, telemedicine allows patients to receive care when attending clinics is not safe, but remote consultations might not allow the same opportunities for communication. However, promising research suggests that rapid and convenient online access to electronic records, including the notes written by clinicians (so-called open notes), might help to support and empower patients.2,3 Most people in the Nordic countries are already offered open notes using patient portals and this practice is growing worldwide.4 From Nov 2, 2020, new federal laws in the USA mandate that providers must extend open notes to all patients,

with a few permitted exemptions. Drawing on findings in oncology settings, we outline what this innovation might mean for patients and oncologists.

Many physicians worry that access to notes in oncology will increase confusion and anxiety among their patients;<sup>5</sup> however, these concerns do not appear to be proven. Since 2009, the practice has been implemented at the University of Texas MD Anderson Cancer Center (Houston, TX, USA), with no reports of patient harm or legal action. In a US survey on radiotherapy, 53 (60%) of 88 oncology patients accessed their notes when given the option, and all of these patients found the notes useful.<sup>6</sup> Commensurate with multiple surveys across primary care and other specialties,<sup>3</sup> 51 (96%) of 53 patients receiving radiotherapy for cancer reported improved understanding about their diagnosis, 50 (94%) had a better understanding of the

treatment risks and side-effects, and 48 (91%) had learnt important information that they had missed during clinical visits. Although six (11%) patients described feeling more worried after receiving their notes, whether their worries were a result of the content of the notes or the access itself was unclear. Moreover, three (6%) patients reported being more confused after receiving their notes and two (4%) patients regretted reading their notes.

Qualitative research reinforces these findings. In Uppsala University Hospital, Uppsala, Sweden, open notes have been implemented since 2012, and patients have appreciated the opportunity to feel more in control of their care than when they did not have access to open notes, with many citing rapid access to results as crucial for their mental wellbeing. As one patient attested, "I'd rather sit and cry at home... rather than having to sit in front of a doctor, shocked without the ability to ask questions". Patients questioned the assumption that accessing notes was worse than the prospects of a cancer diagnosis or of living with the illness. As one individual noted, "if we can manage to have all of these cancer diseases and to live with it, then we can handle reading about it".

How do oncologists feel about the practice of using open notes? In a study done 6 years after the implementation of open notes at an oncology department in Uppsala University Hospital, physicians were divided on whether patient access resulted in more time writing notes, with 37 (58%) of 64 physicians reporting that documentation took longer since the implementation of open notes.<sup>5</sup> Notwithstanding, 47 (73%) physicians believed that patient access to oncology notes was a good idea, with 45 (73%) physicians perceiving that patients felt they had more control of their care. These findings echo the positive experiences of non-oncology clinicians, now replicated in several large-scale surveys.8 Before implementing open notes, many oncology physicians worried that the notes would become less detailed, thereby reducing their usefulness. However, several analyses indicated no evidence exists of objective changes-eg, word length, number of words per sentence, or the positive or negative emotional tone to oncology documentation after patient access was permitted.9

Although the findings are encouraging, the possibility of response bias in surveys and the

restriction of studies to a few medical centres leaves some uncertainty and unanswered questions. For example, does learning about a cancer diagnosis online affect a patient's trust in clinicians? And at what age should minors be given full access to oncology notes?

Nevertheless, the innovation does offer new opportunities for communication. Open notes might prove particularly valuable in cancer care, in which misunderstandings between patients and clinicians about the risks and goals of treatments are especially common.10 Advancements such as incorporating so-called tooltips into online documentation ie, computer graphics that provide pop-out hover boxes of information-could also provide patientfriendly definitions of specific medical terminology without burdening physicians or compromising the quality of records. Oncologists might want training in using clear or supportive language. Patients might also need advice on portal usage, and on the benefits and risks of accessing oncology test results and notes online. In a modest yet meaningful way, this practice might help to empower and signal respect to patients facing fear, unknowns, and life-changing circumstances.

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- 1 Mayor S. COVID-19: impact on cancer workforce and delivery of care. Lancet Oncol 2020: 21: 633.
- 2 Kriegel G, Bell S, Delbanco T. Covid-19 as innovation accelerator: cogenerating telemedicine visit notes with patients. NEJM Catal Innov Care Deliv 2020; published online May 12, 2020. https://doi.org.10.1056/CAT.20.0154.
- 3 Walker J, Leveille S, Bell S, et al. OpenNotes after 7 years: patient experiences with ongoing access to their clinicians' outpatient visit notes. J Med Internet Res 2019; 21: e13876.
- 4 Essén A, Scandurra I, Gerrits R, et al. Patient access to electronic health records: differences across ten countries. Health Policy Technol 2018; 7: 44–56.
- Moll J, Cajander A. Oncology health-care professionals' perceived effects of patient accessible electronic health records 6 years after launch: a survey study at a major university hospital in Sweden. *Health Inform J* 2020: 26: 1392–403.
- 6 Shaverdian N, Chang EM, Chu F-I, et al. Impact of open access to physician notes on radiation oncology patients: results from an exploratory survey. Pract Radiat Oncol 2019; 9: 102–07.
- 7 Rexhepi H, Ahlfeldt R-M, Cajander A, Huvila I. Cancer patients' attitudes and experiences of online access to their electronic medical records: a qualitative study. *Health Inform J* 2018; 24: 115–24.

- 8 DesRoches CM, Leveille S, Bell SK, et al. The views and experiences of clinicians sharing medical record notes with patients. JAMA Netw Open 2020; 3: e201753.
- 9 Alpert JM, Morris BB, Thomson MD, Matin K, Sabo RT, Brown RF. Patient access to clinical notes in oncology: a mixed method analysis of oncologists' attitudes and linguistic characteristics towards notes. Patient Educ Couns 2019; 102: 1917–24.
- 10 Klein WM, Ferrer RA, Kaufman AR. How (or do) people "think" about cancer risk, and why that matters. JAMA Oncol 2020; published online May 21. https://doi.org/10.1001/jamaoncol.2020.0170.



## Gender balance at oncology conferences in China



For more on CSCO and CACA events see http://www.csco.ac. cn/, http://www.caca.org.cn/, and https://www.csmo.org

Female physicians are less often speakers and organisers at major medical conferences than men. Most studies examining gender balance among speakers at various conferences are from North America and Europe. For many specialties, women make up 15-20% of conference speakers, with surgical specialties frequently having the lowest female representation.<sup>1,2</sup> The European Society for Medical Oncology reported an increase in the number of female speakers across international oncology conferences from approximately 25% to 33% between 2000 and 2015.3 Studies in North America and Europe suggest that greater female membership on scientific conference planning committees is associated with an increased proportion of female physician speakers.4 However, compared with data from North America and Europe, less is known about such disparities in the Asian continent, specifically in China. To our knowledge, there are no such studies that have been done to examine gender distribution among medical conference speakers in China, especially at oncology and breast cancer conferences.

In 2018, China accounted for 4-3 million (24%) of new cancer diagnoses and 2-9 million (30%) of cancer mortality, globally.<sup>5</sup> Breast cancer was the most common cause of cancer deaths among women worldwide and is the second most common cause of death due to malignant tumours among women in China.<sup>6</sup>

China has four major oncology conferences. The Chinese Society of Clinical Oncology (CSCO) hosts the two largest annual oncology conferences in Asia, the CSCO meeting (>30 000 participants) and the Breast Oncology Summit (BRCA-CSCO, >3000 participants). The China Anti-Cancer Association (CACA) hosts two events, the annual Chinese Symposium on Medical Oncology (CSMO, >16 000 participants) and the Chinese Conference on Oncology (CCO, >14 000 participants). We aimed to investigate the gender distribution

of speakers and scientific committee members at these four main oncology conferences in China.

We did a retrospective audit of speakers and scientific committee members at CSCO, BRCA-CSCO, CSMO, and CCO between 2009 and 2019. Information was obtained from Chinese-language scientific programmes available on the respective event websites.

Because different events consisted of various presentation formats and types, we defined speakers as keynote or plenary speakers, moderators or panellists, and podium presenters who were listed as part of the main scientific programme. Poster presentations were excluded. Data regarding the total number of abstract submissions and the gender of submitters were not publicly available. We then tallied the speaker's gender for each event for each year, verifying each listed speaker's name on the programme with their gender, if discoverable from publicly searchable online databases of Chinese academics. These databases included the China National Knowledge Infrastructure and the Wanfang and Chinese Science Citation Database. If the information on gender was unavailable in these databases, a general internet search was done. If the gender could not be verified, then these speakers were classified as an unverified gender.

Scientific committee members were defined as chairs or members of programme committees for each event who were responsible for the conference scientific programme and ultimately approved the final roster of speakers. For CSCO and CACA, scientific committee members are chosen by the respective society's presidents each year; also, speakers or scientific committee members are not required to be members of the society for whom they are planning the conference.

Descriptive statistics on the speaker's gender are presented. The Cochran-Armitage trend test assessed the trends in the proportion of speakers and scientific