may well ask if they are providing data to the physician or to a machine via the doctor. Patients should be informed about how their information will be used, and informed consent should be obtained to use their information for the development of future applications. Currently, some institutions obtain consent from patients when they enter the facility to collect and store blood samples and other health-care data as part of the development of biobanks. These biobanks data can generally be used for any type of research on human health, including genomics, biomarker analyses, epidemiology and outcomes research, and the creation of cell lines. In other cases, large technology companies are gaining access to patient data by working with health-care facilities, buying access to image storage repositories or working with insurance companies that have obtained patients' consent for data use. Although there are opt-out clauses in most of these consent forms, it is not always clear to patients and providers what they are consenting to when they sign the informed consent forms.

Patients who do not consent to their data being used for the development of artificial intelligence algorithms or object to the use of their data for this purpose should continue to be accommodated in the health-care system. Opting out should not mean losing out. They should also be allowed to revoke access to their data if they feel that these are being used in ways that were not made expressly clear when initial consent was obtained.

There are no clear regulations about how the data collected are used and shared with third parties, and we currently rely on Institutional Review Boards (IRBs) and ethics committees in institutions to help guide the process. The checks and balances of IRBs are not available in all hospitals and all parts of the world. It is possible that we might require laws such as General Data Protection Regulation (GDPR) tailored for the use of data of individuals in health-care applications to ensure that companies and individuals working in this area remain cognisant of patient privacy at all times. Patient advocacy groups and medical associations will have to work with and guide law makers to make these laws fair to both patients and researchers trying to develop new tools.

As more solutions are developed to assist or replace human readers, one could argue that it is unethical not to allow access to machine learning tools to patients and providers in low-resource settings if the cost of a suite of solutions is lower than employing human readers and if these tools can help shorten diagnostic times and ensure prompt management. On a personal note, in my own practice, my colleagues and I use semi-automated co-registration and subtraction tools to compare the size of ventricles or tumour masses at different timepoints in our patients, as we find this is more accurate than manual visual assessment. I cannot see why all patients should not have access to these tools if they have been shown to be better than human assessment alone.

As the performance of artificial intelligence tools starts surpassing those of humans performing a similar task, patients will request direct or indirect access to such applications. For example, if a patient with a tumour wants to know the likelihood of malignancy, they may wish to use a suite of applications made available online before consenting to biopsy. As another example, patients may request access to online applications for automated detection of a focal abnormality causing seizures, where there is a large variation in the accuracy of imaging studies when scans are read by radiologists with varying levels of experience.

Ethical issues surrounding machine learning and artificial intelligence are complex and deserve a lot of thought before incorporating them into routine clinical care. It would be prudent to include patient advocates and technically savvy ethics experts in decision making at all levels to pre-emptively come up with solutions to potential ethical challenges in this field. And on a practical note, I suggest checking in with your own institution and confirming that they have a clear policy of how they use and share patient data, and educating your patients about the data use consent forms they are asked to sign.

Sanjay P Prabhu

Digital Oncology
Crowdfunding for cancer research: the TRACe campaign as an example

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Over the past 7 years, research funding has witnessed a changing trend. Besides available competitive research funding such as Horizon 2020 (Europe), National Institutes of Health (USA), National Health Service (UK) grants, and other public research funding programmes around the world, including those from charitable organisations, researchers have started to engage in crowdfunding activities to look for alternative sources of funding. Management of a scientific grant, based on developing a technical project proposal that will be

examined by a scientific committee of experts, is in stark contrast to developing a crowdfunding campaign to fund research, which requires the general public to engage with the research project iHelp. Despite the novelty of crowdfunding to fund science, researchers should not be discouraged from setting up their own campaigns. Crowdfunding is an innovative and creative way to finance scientific research and offers interesting opportunities for cancer research because of the cost of the techniques involved, such as single-cell analyses, sequencing, and omics approaches, which require access to large budgets. Crowdfunding can also offer exciting funding opportunities for early career researchers, who are at a disadvantage when competing for traditional grants. In this Perspective, we share our experience of launching a crowdfunding campaign to fund cancer research and facilitate science outreach between the public and researchers during project's lifetime. TRACe, initiated by the Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori (IRST-IRCCS; Meldola, Italy), gained traction in light of the high competition for publicly funded grants in the preliminary stage of the project, and the high cost of the proposed single-cell analyses. The core project aims to understand the contribution of circulating tumour cells to the metastatic process and their potential use as a clinical diagnostic for oesophageal and colon cancers.

Our experience highlights the benefit of crowdfunding to translational research teams and aims to provide some practical guidelines for putting together a successful crowdfunding campaign that started from scratch. A crowdfunding campaign consists of many different elements (appendix), which require a multidisciplinary team, including researchers, grant officers, and communication officers. A key goal of the pre-launch phase of a scientific campaign is to translate the specialised research project into lay language. Therefore, key to a successful crowdfunding campaign is the communication strategy, which promotes high visibility of the project, creates a broad network of contacts, and engages with the public by involving them in the project from its inception throughout its development, to the final results and publication. The TRACe team spent around 3 months to plan the pre-launch of the campaign.

Our crowd was assembled from three distinct target groups that shared a potential interest in TRACe: a pre-existing network of people who were already engaged with more traditional research donation schemes, the community that visited our online crowdfunding platform, and small and medium-sized companies and not-for-profit organisations engaged via messaging on social media channels and direct correspondence to the TRACe team during the crowdfunding campaign.

Visibility of the campaign was ensured by constant communication activity both online (Facebook, Twitter and Instagram) and offline (news outlets and press releases) throughout the campaign. The online campaign dissemination started about 2 weeks before the official launch date with the aim of drawing attention and generating hype in the public ahead of the launch. To involve the press in the launch of the campaign, we sought the support of a regional consortium for innovation and technology transfer (ASTER, Emilia-Romagna, Italy), which collaborated with the TRACe team on the launch press release.

It is essential to choose the most fitting platform for your project. We opted for a crowdfunding platform hosting projects in different areas and well known locally in order to strengthen the territorial identity of the TRACe campaign. We added to the webpage a video that welcomed the public as part of the research team to build a sense of community while avoiding more sensitive messages associated with the disease or the patients' condition. The video represented a powerful and direct vehicle for dissemination and the TRACE crowdfunding webpage managed to attract about 4000 visitors during the active phase of the campaign.

The TRACe campaign was launched in March, 2017. We opted for a reward-based crowdfunding system with a target goal of €20 000 to be collected in 90 days, of which less than €1000 was planned to support campaign costs. The pre-launch dissemination had extensive engagement on Facebook, with 10 000 people visiting the TRACe Facebook page on launch day. TRACe's social media channels gathered a community of more than 1000 people and associations. Contributions often came with private messages of support and public engagement was expressed through posts on social media. The campaign raised €25 095, 125% of its target, thanks to donations by 200 contributors (figure A), including private donors (€9460 [38%] of 25 095), NGOs (€5135 [20%]), and small and medium-sized companies (€10 500 [42%]). This result shows how individual donations can match those of companies if the communication strategy targets individuals appropriately. The time analysis (figure B) shows that during the first month after the launch the contributions made by private donations were comparable to those of companies. During the following months, there was a drop in individual donations, which was counterbalanced by donations from companies and NGOs. This could be due to faster saturation of private donations on one hand, and the longer lead-in time required by NGOs and companies to settle a donation, on the other hand. Traditional dissemination led to coverage in local and national newspapers, blogs and newscasts, through the partnership with ASTER, and led to the invitation to present TRACe at external events and conferences on crowdfunding for research.

In our experience, creation of a multidisciplinary team was key to the success of TRACe. Support from

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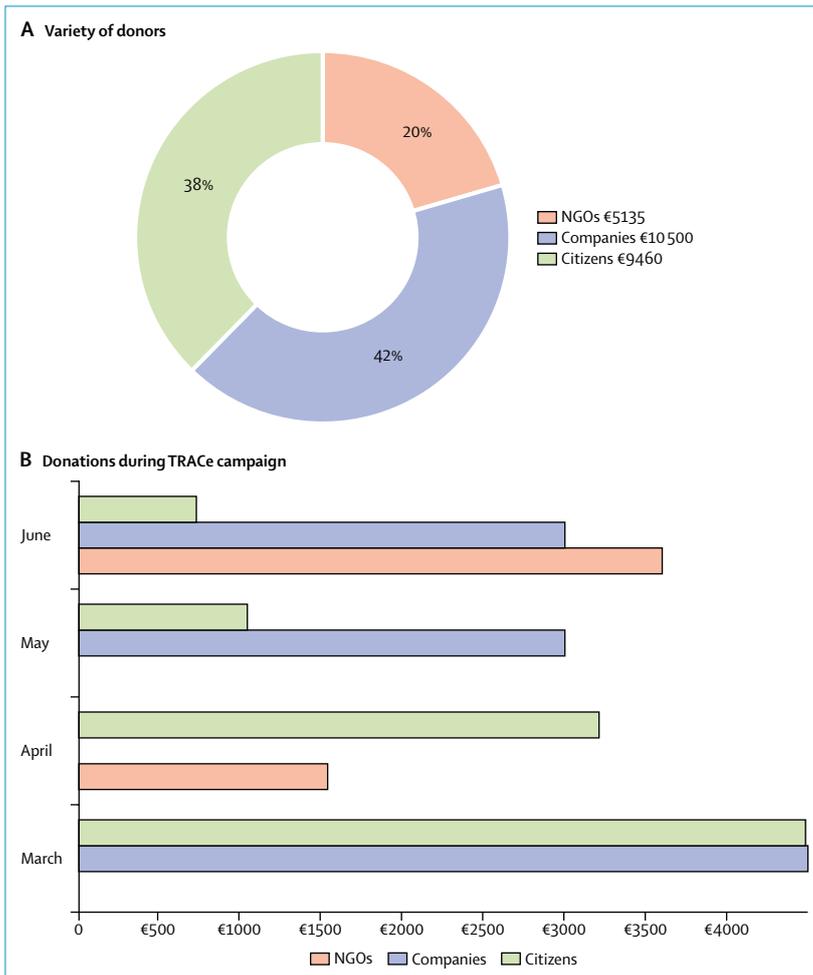
See **Online** for appendix

Figure: Analysis of donations given to the TRACe campaign
(A) TRACe Facebook page benchmark including the pre-launch and active crowdfunding campaign periods.
(B) Breakdown of total contributions from the TRACe campaign donors. (C) Monthly donations by different types
of donors during the active period of the campaign. NGO=non-governmental organisation.

to success. A crowdfunding campaign based solely on online communication will miss potential donors who might be unfamiliar with the internet and social media. It is also important to have a plan B for when donations drop or stop before reaching the target. Analyse what are the likely causes for the slow down, brainstorm with your team, and come up with creative and engaging solutions.

One of the main concerns about crowdfunding to fund research are the ethical controversies surrounding this practice, including fraud and misinformation spreading, allocation fairness of funds, and perpetuating systemic injustice. Therefore, a specific set of measures must be built into the design and processes of a crowdfunding campaign before its launch to counteract potential pitfalls. For example, before setting up the campaign, the TRACe project was approved by an independent ethics committee. Researchers who embark on crowdfunding must abide by recognised standards and best practices of research integrity. However, crowdfunding raises novel challenges for research integrity—eg, in relation to the level of scrutiny that a crowdfunded project is subjected to. To prevent the public from funding low-quality, unethical, or unrealistic research projects, institutions where the crowdfunded research will take place must safeguard the underlying integrity by setting up internal project review and approval processes before the campaign goes live. Crowdfunding for science not only represents a novel funding mechanism but, if managed appropriately, could also contribute to science outreach and public engagement. Crowdfunding may prove particularly beneficial for early career researchers and is particularly suited to spur academia–industry cooperation, and knowledge and technology transfer.

The increasing burden of cancer worldwide will motivate sustained research in this field. Although the majority of funding still comes from traditional sources, crowdfunding could, if appropriately managed, play a supportive role in scientific funding and raise public awareness about cancer as a global health priority.

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the research institution allowed us to bring together expertise from different departments, reduce the associated costs, and accredit the scientific validity of the project. The communication strategy based on online and offline approaches, and selection of the most appropriate crowdfunding platform, are other keys