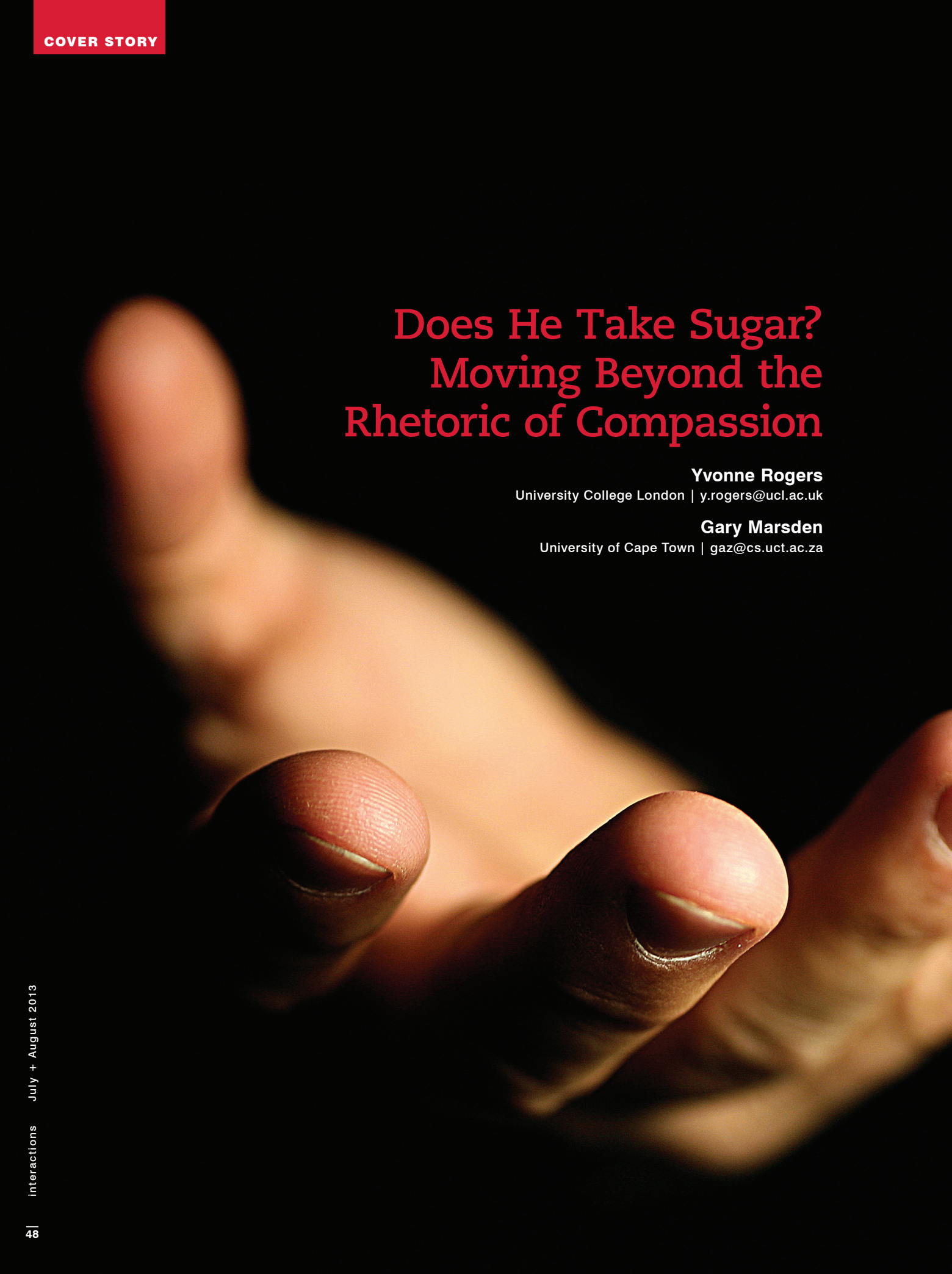

Does He Take Sugar? Moving Beyond the Rhetoric of Compassion

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"Does he take sugar in his tea?"
Hello, why not ask me?
I might have a disability,
But to answer for myself I still have the ability.
Just 'cos I'm not stood up like you:
Does not mean there is very little for myself that I can do…

—Michael W. Williams,
"Connah's Quay"

For 20 years, up until the late 1990s, the U.K.'s Radio 4 ran a weekly series called "Does He Take Sugar?" that presented an in-depth treatment of disability. The title of the program refers to when someone asks the carer about sugar instead of directly asking the person who is being offered a hot drink. It captures the sentiment of talking about someone who is disabled in the third person, while in their presence, regardless of whether that person can speak for him- or herself. The program brought attention to this kind of "overlooking" and gave disabled people a voice (it also had a disabled presenter). It did wonders for helping "abled" people realize how to listen, talk to, and engage with disabled people just like anyone else.

Likewise, HCI has come from a place where our attempts to help others who are "worse off than us" have often ended up being framed in a similar third-person vein. The tendency has been to develop technological solutions for them based on our understanding of what they need, by providing for a lack of something. This could be technical (e.g., access to the Internet, computers, mobile airtime), a declining ability that comes with age (e.g., sight, looking after oneself, memory), or a physical or mental disability (e.g., autism, depression). While many projects have sensitively and successfully demonstrated how novel technologies can support and enhance people's lives (e.g., [1]), some are fronted with a third-person perspective, asking questions such as, "What technology do they need?" And, mostly, we have designed solutions to compensate and overcome rather than to innovate.

Although the wider field of HCI has moved forward in its thinking, with a focus now on ethnographic methods and co-design, here we explicate our growing unease with the *rhetoric of compassion* that underlies much of our wanting to help people. So although HCI may be more attuned to working with people, there still remains a remnant of "sugar thinking" that we will explore in two areas of research—assisted living and information and communication technologies for development (ICT4D)—to illustrate our concerns.

As an alternative to focusing on need, we outline an approach that promotes empowerment through technology, enabling other people to become better equipped to the point where they can innovate for themselves. To achieve this, we propose framing HCI research that embraces a *rhetoric of engagement*. By this we mean talking about, demonstrating, and eventually handing over to people our toolkits, know-how, and technologies so they can decide what to do with them in their own contexts. The people we engage with can be those living in poverty, without access to the Internet, the elderly, the disabled, and so on—but also those whose professional role is to teach, care for, and work with them. In so doing, we see our role as HCI researchers to remain as researchers, and to put our efforts

Photograph by Jihopgood

We need to be mindful of what we can offer as researchers and how we can switch our focus from helping *others to* empowering *others.*

into what we are best at and feel comfortable with—that is, being inventors, imagineers, and purveyors of new interaction design tools, interfaces, and technologies. We leave the appropriation and adapting of those technologies to the people whose lives they might enhance. We empower them to engage with us, not just in design, but in co-creation and clear articulation of their technology desires.

Lending a Helping Hand

Much early HCI research was motivated by a desire to improve the lives and livelihoods of those who were not as well off as us [2]. Researchers sought ways of developing technologies that could address the range of inequalities in society, focusing their efforts on people who were disadvantaged or challenged in some way, such as being poor, autistic, frail, blind, illiterate, elderly, disabled, starving, lacking access to the Internet, suffering from Alzheimer's and other memory problems, living in developing countries, and so on. Some notable achievements include One Laptop Per Child [3,4], assistive technology [1], and universal accessibility [5].

Over the years, a number of governmental, nonprofit, and funding bodies have set up initiatives and conferences to address the needs of those described here. For example, the Ambient Assisted Living Joint Programme (AALJP), started in 2008 with 23 European countries, has been developing programs to improve quality of life for older adults through the application of information and communication technology (ICT), while the International Federation for Information Processing (IFIP) has established a number of working groups, such as the Social Implications of Computers in Developing Countries (IFIP WG9.4), as venues for scholars and practitioners who are concerned with how ICT affects social development. Collectively, they have legitimized and helped establish ICT for others as credible and mainstream areas of research in HCI.

The take-up in HCI has, understandably, been huge. Many research teams across the globe have conducted numerous research projects, exploring how technology can play a role in helping others, from ending poverty to helping children with autism learn social skills. The projects vary considerably in terms of their motivation, the kind of research conducted, the methodological approaches adopted, and their actual impact.

A Growing Sense of Unease

In some sense, this article is a response to Alex Taylor, who discussed the "turn out there"—efforts to expand the remit of HCI to wider concerns [6]. In his paper he expressed his unease when HCI researchers seek to understand the lives of others by framing issues with their own theories and orderings, in the same way that some accuse anthropologists of overcomplicating what is out there. In his conclusion he argued that we are very much part and parcel of the interactions we are studying and designing for, and hence we should provide practical and ordinary tools rather than fanciful theorizing. Moreover, he believes we should be bettering people's lives, but he agonizes over how we should do this: "How will we know it when we see it, and how will we know whose better it is?"

To address these questions and overcome our own growing unease with HCI's third-person agenda of

helping others, we argue that we need first to sensitize ourselves to the assumptions inherent in our research questions and the challenges posed to us by our funding bodies. We need then to be mindful of what we can offer as researchers and how we can switch our focus from *helping* others to *empowering* others. And this involves shifting from HCI's default rhetoric of compassion to a different discourse and documentation of our research that is more akin to a rhetoric of engagement.

The rhetoric of compassion in HCI [7,8] was originally used to refer to one research community's views (e.g., psychologists, sociologists, and anthropologists joining the field of HCI) of what was needed to be done by another community (e.g., software developers, interaction designers). HCI saw its responsibility as representing the user in development and subsequently empowering the designers in HCI [9]. Here, we use the phrase more specifically to refer to HCI research concerned with representing and helping others who are worse off in some way when compared with the researchers themselves (i.e., those employed in universities, consultancies, IT companies). The list of such groups is extensive and includes those who lack access to the Internet in rural Africa or are unable to look after themselves at their home in the U.K. ICT is seen as a way of helping overcome a lack through providing a range of applications and tools that support new forms of connecting with each other and new ways of learning.

While the efforts of those involved in representing others is laudable, we are concerned that this form of compassion perpetuates the asymmetrical relationship between those who have and those who have not, underlying an uneasy dependency between those who need and those who can help. Over the years, we have seen how increasingly research slips into the third-person mode of "Does he take sugar?" HCI researchers take it upon themselves, with varying degrees of user involvement or participation, to work out ways of helping those we have identified as potential user groups whose lives we can improve through our various technological interventions, such as sensing deviations from their everyday routines and providing up-to-date community news in their streets. It may be, though, that they do not want to have their toothpaste usage monitored or glowing lamps or digital billboards showing local activities in their neighborhoods and homes [10].

No matter how well we might construct our research to be inclusive, our thoughts and models can be warped into a third-person way of thinking right from the proposal stage. Here is an excerpt from a DFID grant proposal: "ICTs are therefore essential components of the participation, transparency, and good governance, increasingly seen as the crucial basis for development and poverty reduction. However, the impact of ICTs on the lives of poor people can be both positive and negative … This programme addresses the market failure of investment into a global public good: research in poverty-focused ICT4D."

While the goals of the project funding are worthy, there is an assumption here about the participants in the research, namely that they are poor and that it is the researchers who understand ICT's need to assess impact.

To further illustrate our discomfort with the rhetoric and practice surrounding those whose lives we choose to improve through technology, we turn our attention to two areas of research we have been working in: ambient assisted living and information and communication technologies for development (ICT4D).

Ambient Assisted Living and ICT4D

Our two research areas have been named to reflect the way in which technology can help: assisted living and information and communication technologies for development (ICT4D).

Ambient assisted living. Back in 2006, one of us [11] wrote about our concerns with the push toward developing assistive technologies that sense the movement of elderly people and alert others should the system detect any anomalies from a prescribed pattern of routines. A number of early ubiquitous computing systems were built to monitor and keep an eye on the elderly (e.g., [12]) and the physically and mentally disabled (e.g., [13]). The habits, health, and mishaps of such people were recorded, tracked, and presented via remote monitors to the families, caregivers, and other people responsible for them, who could then use the updated information to make decisions about whether to intervene or administer alternative forms of medical care or help.

At the time, I noted the dangers and moral concerns surrounding this ambient assisted approach: probing too far into the lives of less able people, resulting in—albeit unintentionally—extreme forms of recording, tracking, and monitoring over which the monitored people had no control [11]. An example used to illustrate this problem-

atic relationship highlighted the lengths to which one group of researchers went to help with the care of old people in a residential care home [14]. A variety of monitoring devices were installed in their home, including badges worn by patients and caregivers and switches on the room doors that detected when they were open or closed. Load sensors were also used to measure and monitor weight changes of the elderly while in their beds; the primary aim was to track trends in weight gain or loss over time. But the sensors could also be used to infer how well someone was sleeping. If significant movement was detected during the night, this was intended to enable a caregiver to see whether the person was having trouble sleeping (but, equally, if there was a huge increase in weight, this could be inferred as someone else getting into or onto the bed).

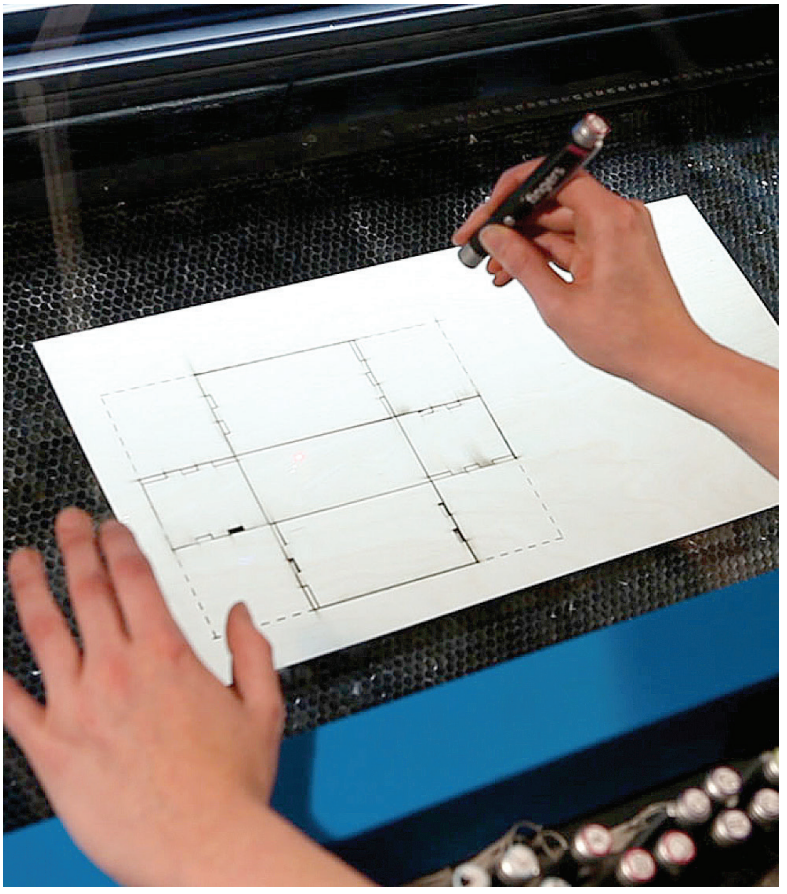
Though the motives behind these projects were altruistic, they were of the third-person variety, overlooking the ways in which people's privacy and self-respect might be violated. Is it right to be videotaping and sensing people when they are sleeping, eating, and so on, especially when they are not at their best [15]? Is it right to be providing information to family members about their grandma's sleeping habits, especially if it can be inferred from the sensed data that she might have gotten into bed with another patient, which none of the vested parties might want to share.

Six years on, the same moral concerns persist, arguably more so as assisted-living systems are increasingly being implemented in care homes and ordinary homes, and governments and industrial research have continued to pour money into projects worldwide. There is a push toward achieving "market penetration." The reason being, at least from a European perspective, is that "this is vital because otherwise there is a risk that solutions from Japan, China, South Korea, and other countries will come into Europe and dominate the market, which is potentially huge. A race is on, and we in Europe have to be quick to identify markets and assist small and medium enterprises (SMEs) with that, as well as with the development of their products" [16].

The driving force of commercial competition motivating the research also adds to our unease. Liam Bannon [17] further raises many of the ethical dilemmas with the seemingly relentless push for more ambient assisted living. Today's agenda seems to be very much the same: to find ways of introducing new technologies into the home to enable elderly people to live independently, with a view to providing them with a better quality of life at home than in an institution, but also not becoming a burden on the state. Bannon questions the rhetoric of whether this use of technology can empower older people by letting them live in their own homes for longer, pointing out how many of the ubiquitous technologies that have been prototyped and commercialized to promote a 24/7 remote monitoring of elderly people (including how much they are drinking, how often they go to the bathroom, etc.) are insidious. While these innovations are potentially life-saving and reassuring for family members, it can be difficult to see how sending SMS alerts to carers helps the elderly individuals. Does it improve the quality of their life? If so, in what ways? Has anyone done a thorough, before-and-after in-the-wild study on ambient assisted technology? And what if the questions were framed differently from the assumptions about how it enables the elderly to remain independent in their own homes? How does it change the guilt burden for family members, who are constantly being reminded they are not there through text messages? How does it improve the quality of life for those living by themselves for longer?

The framing of such technology is very much in the "Does he need sugar?" third-person mode—however well-meaning by family members, the social services, or insurance companies—overlooking how elderly people who live alone at home might want to live, and that they might be more interested in having social contact with others, a sense of belonging to a community, a sense of giving something back to society, and ways to be actively engaged in their lives than having their health and movements monitored. How people, themselves, could be engaged in designing and setting up home-monitoring technologies has received very little attention.

The focus of other research on aging and technology has equally been on augmenting frailty, where projects have designed "smart" technologies intended to help the elderly take their pills regularly, exercise more, and eat better. It, too, raises the question of whether this approach is right. In contrast, we argue for an approach that focuses on engagement with a view to empowerment, taking as its starting point how technology can be designed and created *by* elderly people, themselves, for more life-affirming activities, such as reminiscing, generating digital content, and socializing. A recent study that adopted a more engaging stance



▸ Figure 1. Constructable users interact by drafting directly on the workpiece with hand-held lasers that have a simple three-button user interface (see [22]).

found when adults in their eighties and nineties were shown how to create and share personally meaningful digital content, it helped them build connections with their peers [18]. It seems the act of engaging with the technology to create something rather than using it for monitoring or consumption is key. Instead of *us* designing for old people's frailty, we argue for older people themselves being more involved in designing and using technology to create applications and experiences we have not cooked up or thought of.

ICT for development. One of us, in a paper titled "People Are People, but Technology Is Not Technology," warns of the problems in seeing a user's need and attempting to meet that need without first asking the community if they, too, recognize that need [19]. Even when a researcher engages with the community in co-design to create a system to meet the need, we can end up with an easy-to-use system with no users. In effect, we have decided the community needs sugar and designed the perfect sugar-delivery system, only to find the community would rather have milk.

We are guilty of this in our own work, where we built a community notice board system, as we perceived that the community lacked jobs. The community in question was built around a skills training center for the unemployed. Therefore, we felt that a lack of employment was of concern to the community. When we built the community an electronic bulletin board, there was indeed some job-posting activity, but the bulk of postings were about locally created choir music. Despite our external perception, what the community really needed was a way to celebrate the music they created.

But how then do we allow the community to co-create with us? The communities we wish to engage with often have low technical sophistication and lack the abilities to set up new forms of technology or express themselves in a way that lets them sufficiently influence the creation process. While it is an idealized situation for every community to create its own technology, we view the path to that end as beginning with the type of rhetoric and ideas that we in the HCI community employ.

A hand-over approach. We argue that technology-led and user-centered/participatory design methods do not go far enough in democratizing the creation of technology. While they can respectively provide impressive solutions and useful feedback in the early stages of design, the researcher is still very much in the driving seat, running and controlling the research agenda and developing the technologies. Our proposed hand-over approach is intended to move beyond these researcher-led approaches by framing the research agenda quite differently, engaging with people differently, and configuring research and ICT differently.

First, along with others, we think it is high time we abandoned the deficit and compensation model that has been behind much technology development and design thinking. Instead, we frame our research to consider how new technologies can be designed and appropriated to extend people's ability to learn, make decisions, reason, create, solve problems, and generate innovative ideas. Second, we are interested in how we can open up the design space more by showing what new technology toolkits can do and through running technology workshops. In so doing, our role changes: Rather than being in control, helping others through building for them or taking on board their ideas and feedback and acting on their behalf, we propose that the modus operandi should be to demonstrate methods, toolkits, and technologies to people. Third, the challenge for HCI researchers is to make ever more accessible, creative, and affordable technological toolkits, opening up new possibilities.

Some might ask, however, where that leaves us as researchers, especially those of us who can't make or build but still want to help change the world through IT. Going out there and reporting back to the HCI community, using our framings and trained eyes, on how different or worse off others are in Africa or a run-down council estate in London compared with us—and what we think would be good to do to help out—does not help. Our proposal is to switch from representing others to engaging more with them, not through acting on behalf of others but by providing more of a mentoring and demonstrating role, showing what is possible, and galvanizing groups and communities in learning about and realizing the opportunities that the new toolkits and technologies provide. The choices regarding what to do next are up to them.

The Way Forward: Empowerment and Leapfrog

Ten years ago, Ben Shneiderman presented his vision of the new computing, outlining how HCI researchers could develop tools to empower users, with a focus on what users want to do in their lives [20]. More recently, Harold Nelson and Erik Stolterman put forward the view that design should be about being "in service" to others rather than "helping" people in need, the emphasis being on human values that support human dignity, equity, creativity, and individuality [21]. Here, we argue for going even further: empowering people to engage with technology in innovative ways that stretch others' imagination and tap into their wisdom and worldviews.

One approach is to lower the entry bar to creative technology by developing ever more creative and far-reaching technology toolkits (following the success of Arduino, Makey Makey, Scratch, Sense, Lily Pad, Raspberry Pi). The target would be not just kids learning to program, but also others who may be retired and don't have much money but who would like to be more creative, to take part, and to be shown how. And let's not call it new forms of computer literacy but rather technology leapfrog. Our hunch is that these toolkits open up a new way of engaging others in the technology-creation process. Our methods to date have confined agency to the HCI researchers. We want to explore how we can hand over that agency to people who want it. To date, participatory design has allowed teachers and others to take part in design. We now want to allow them to take part in creation.

We can achieve this by continuing to create usable electronic toolkits together with making new, easy-to-use interfaces for material-cutting tools, such as Constructable [22], which provides a novel, laser pen-based interface instead of CAD software for controlling the laser cutting (Figure 1). Until now, workshops at fab labs and universities have largely been offered to students, schoolchildren, and designers. But people from all walks of life should be able to take

an active part in controlling their technological setups, their evolution, and their destruction. The benefits of these toolkits should be clear: enabling forms of information flow (i.e., ways and means of accessing information) and information management (i.e., ways of storing, recording, and reusing information) quite different from earlier technologies, making it possible for people to subsequently develop their own systems that can make a difference in their lives. In making these toolkits available, there should be an emphasis on providing the means by which to augment and extend existing practices of working, learning, and everyday life. Our vision is to see if it is possible to transform current maker and DIY electronics culture to one that is broader and, important, can be fused and combined with a diversity of other skills and crafts, such as cooking, cloth making, energy generation, publishing, and toy making (see [23]). By adding new tools, techniques, and materials from crafts to the technology maker's palette (or vice versa), the possibilities of creativity are amplified.

Consider, too, what is happening in poor communities in Africa, where instead of people wanting hand-me-down PCs from the West, they are purchasing cheap mobile phones. The Nokia 1100 handset (Figure 2) became the bestselling handset of all time (250 million sold), as it was the first to include a flashlight. If you live in the developing world, where nighttime illumination is scarce, a flashlight is a critical purchase. So where telecenters (designed to give people access to PCs) have largely failed in Africa, cellular handsets are ubiquitous. As smartphones become more prevalent, too, we see limitations in

▸ Figure 2. The Nokia 1100.

▸ Figure 3. Examples of African design. (top) An oil lamp made from a tin can. (bottom) A self-closing gate made from a piece of broken conveyor belt.

current smartphone design. Many require docking or syncing with a desktop computer to work properly. However, that is not possible for most handset owners in Africa. So what would a handset look like if it were devoid of the heritage and restrictions of current designs? We propose that the only way to find out is to empower those users to create and design such a handset.

Creativity abounds in Africa, despite the lack of resources. In Figure 3, for example, we see a self-closing gate made from a piece of broken conveyor belt and an oil lamp constructed from a tin can.

The excellent AfriGadget blog (http://www.afrigadget.com/) offers many examples of new technologies created for Africa by Africans. A casual glance through the site shows how empowering people with the tools to solve their own problems leads to much more appropriate and effective solutions.

The idea is that technological innovation can come from anywhere, that it is not a one-way street from the developed to the developing countries, but rather that it can transfer, for example, from rural China to high-tech Japan, or from rural Africa to the U.S.

Our vision is to make computers engaging, accessible, and exciting to as many people as possible. This includes people who are getting older and retiring. One barrier to overcome is the fear of technology some people have who were not exposed to it when younger. Here, we think the ubiquitous devices of the past decade have come a long way in helping people who saw themselves as "not being very technological." We now see such people excited to post to Facebook and Twitter to keep in touch, logging onto the Internet, using

touch screens to play games, and consuming and producing media. Instead of us designing for senior frailties, we see older people themselves becoming more involved in thinking about the design and the use of technology to solve problems they care about, such as loneliness and isolation. A further ambition is for them to teach others—for example, their grandchildren or disaffected youth—about the new technologies, an idea that was proposed in a recent workshop we had with some elders when exploring the new technology toolkits. The elderly have considerable wisdom and creativity that can be tapped into. We think by providing them with new computational resources, tools, and materials, they can see opportunities to meld, mold, and mix in ways different from those of younger generations.

Summary

Our approach is to rethink HCI research in the wild—not in terms of framing or determining how to design and evaluate new technological interventions in situ, but rather in terms of the lives of people in the wild. This entails rethinking how to teach interaction design, how we frame problems, what our expectations are, the way HCI knowledge is used, the way theory is applied, the way studios/classes are run, and what interdisciplinarity means in this context. It also implies the need to shift from being bogged down as a prescriptive discipline, telling others what to do and not to do (the dos and don'ts and "we are the experts" mentality) to a more empathetic, encouraging, and excited community.

We see this shift toward different forms of engagement as part of a broader shift in HCI toward moving its research agenda into the wild [24,25]. As we moved from design to co-design, we can shift from creation to co-creation. In addition to changing our methods to adapt to in the wild, we need to rethink our motivations for how and why we are creating technologies in new locations and with new users. In sum, we argue for the following:

- Stop thinking with a third-person, "Does he take technology?" mentality when it comes to the creation of technology.
- As a discipline, add to our repertoire of roles; encourage researchers to think about how to facilitate co-creation sessions.
- Continue to create new forms of toolkits that promote creativity and can be adapted by a wide range of users, from care homes in Europe to rural villages in India.

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