FROM THE EDITORS

We’ve had a bit of a break here at Innovia; not least because of the beautiful, very hot weather most of Europe has been experiencing lately (albeit, sadly, it does remind us of climate change). The Innovia Foundation is also a truly international project, since in practice we are rarely in one place. Coordinating Newsletter production can therefore be somewhat of a challenge, but as a matter of fact, internationality is one of our biggest qualities and exactly why we love doing it. Naturally, contributions this summer are equally manifold and come from corners all over the world. So in this vein, we would like to welcome all readers to this – we admit belated – 23rd issue.

Notions of normalcy are foremost social as well as cultural constructions. The idea of what is considered normal or abnormal, physically fit or out-of-shape, beautiful or unsightly, can vary from country to country and from one cultural context to the next. It is partly through these socio-cultural concepts that societies develop an often rather specific politics of the body, i.e. the definition of fixed norms and guidelines as well as the development of social policies and campaigns surrounding these benchmarks. It has often been argued that while being deeply steeped in the hegemony of neoliberal structures, this progression of events has led to individuals adapting their bodies and selves accordingly. Those strategies of adapting to a rather self-centred environment of normalcy become technologies of the self. The term can take on various meanings – conceptually (a sort of adjustment ‘to fit in’) as well as literally (an actual technology used for the purpose of adjusting oneself). The latter development seems
to have become even more apparent over the last decade or so. Issue 23 touches upon these themes in various ways. How are questions of normalcy disguised when thinking about cultural concepts of health and dis-/ability?

We start off with Stuart Blume’s article ‘Parenting a deaf child in Ecuador’. This piece relates to the study project that he carried out in Cuenca, and which he first introduced in issue 21 of the Newsletter in 2013. The study concerned itself with the experiences of Ecuadorian parents with deaf or hard of hearing children, and how the diagnosis of their children had affected them. The results of the study were unexpected, so do read on.

Questions of normalcy come alive in conjunction with what falls ‘outside of the box’ – depending on from where you look and what is being defined as ‘normal’. Zoe Goldstein was very fortunate to meet with and speak to Sung Kuk Kang, the only disabled professional dancer and performer in Korea. While he consciously attempts to challenge negative attitudes towards people with disabilities through his performances, he is also wary of the preconceptions that come with the ‘disability label’. Zoe’s article explores his art and motivations, whilst also drawing on Kang’s personal reflections on notions of normalcy.

Medicine is perhaps one of those realms that is less concerned with narcissistic notions of adaptation to social norms, but is rather foremost about the wellbeing and longevity of patients. Nevertheless, the latest technologies are often experimented with in the hope of achieving improved quality of life and/or rehabilitating the body. In her piece ‘Is Stem Cell Therapy a lifesaver? Patients experiences of and views on stem cell therapy in China’, Suli Sui presents the results of her ethnographic study on this experimental therapy in China. She documents the struggles as well as some of the potential benefits of the technology for the Chinese patient community.

Last but not least, Gabija Didžiokaitė writes about ‘Digital devices for knowing the self: the latest trends in self-tracking and their implications’. While the action of tracking to fit within certain standards – medical or personal – has always been around, the novelty of self-tracking, Gabija argues, are the devices used as well as the community that exists around these ‘wearable computers’. A form-fitting finale for an issue concerned with technologies of the self, we think.

We end this newsletter with a sad note about the unexpected and untimely death of John Pickstone, a long-term Innovia supporter and personal friend of Stuart. This is followed by the usual list of relevant announcements for the upcoming (academic) year. Please do feel free to contact us if you wish to contribute to one of our forthcoming issues or if you have any questions and/or ideas for topics and improvements. We at Innovia wish you a very lovely rest of the summer … or perhaps winter, depending on where you are.

Marianne and Zoe

PARENTING A DEAF CHILD IN ECUADOR
Stuart Blume

In Issue 21 of the Newsletter, in September 2013, I wrote about the start of the project I was to carry out at the University of Cuenca in Ecuador. It was to be a study of how parents deal with their child being diagnosed as deaf or hard of hearing, though I found it quite difficult to
decide how exactly I would function as a researcher or what exactly my role would be. Now the project is finished. Between November 2013 and March 2014 we – that is to say Liliana Brito, Maria-Esther Peréz and I – interviewed the principal carers (parents or grandparents) of 19 children, aged between 3 and 15 years, all of whom had been diagnosed as deaf or hard of hearing, and were living in or near Cuenca. Our questions covered issues such as when and how they had received the diagnosis, how it had affected them, what support and guidance they had received, the decisions they had made, and their hopes and fears for the future. For someone whose knowledge of parenting a deaf child comes from experience in Europe, and from a literature almost exclusively reflecting what happens in advanced industrial countries, the results came as a bit of a shock. The experience of many of the Ecuadorian parents we interviewed was nothing like what is found in the literature.

How had the child’s deafness come to light? At some point in the child’s early life its mother (or father or grandmother) had begun to suspect that there was something wrong with the child’s hearing. The search for a diagnosis then began. Most of the children in our study were medically diagnosed as deaf or hearing impaired at the age of a few months (though a few were much older).

What did obtaining a diagnosis involve? Experiences were very diverse. There were parents who had travelled a long and complicated route. Often doubting the diagnosis they were first given, they moved purposefully from one doctor, hospital or clinic to another in search of a diagnosis they could trust. Doing this required resources, social and informational as well as financial. These parents had to mobilise their social networks in order to find expert help. Even so, dealing with initial misdiagnoses, the lack of information they were given and the often insensitive manner in which they were treated had destroyed their confidence in the health care system.

There were others who were satisfied with how they’d been treated and had confidence in the diagnosis they’d received. In some cases, the diagnosis came as no surprise because deafness was already present in the family. In other cases, the diagnosis was accepted because life had always been hard, misfortune always round the corner and resources of all kinds were lacking. The experiences of families like these are not reflected in the literature. Moreover, North American and European authors take for granted that a child diagnosed as deaf lives with two parents who (at least in principle) share the responsibility for its upbringing. In the Ecuadorian context, household structures are variable, often fluid and changing (as partners leave and return). In this study, nearly half of the children did not live with both parents. In some cases, the diagnosis actually led to a change in the household structure as fathers – unable to face life with a deaf child – simply left. Uncertainty is arguably one of the few unchanging features of the lives of very poor people. Many studies focusing on the diagnosis of a child as disabled or deaf tell us that it ‘changed the equilibrium in the family’ or that parents tried to ‘regain predictability and control’ in their lives. For many families in our study, however, this does not apply since they might never have had ‘equilibrium’, ‘control’ or ‘predictability’ in their lives. In their case, the deaf child simply brings additional uncertainty.

The course of action that professionals recommend often demands great sacrifices from families that may not even have the money to replace the batteries in their child’s hearing aid. Many parents were told that the cochlear
implant was the only solution for their child; a miracle that would make their child hear. This is dangerous in two ways. Firstly, the cochlear implant is not a miracle and exaggerated expectations can only lead to disappointment. Secondly, if, for whatever reason, the child cannot get an implant, parents are likely to suffer greatly and unnecessarily.

Few parents had any idea of what having a hearing impaired child would mean to them. Where could they turn for advice and support? The doctors and audiologists whom they first met tended only to recommend an implant or hearing aids. Some extended families could provide emotional and practical support, as well as access to well-informed networks. Such families were a great help to parents trying to cope. However, other parents and grandparents, often from poor families, spoke of resentment in the extended family over yet another burden being added to their lives. For example, one father explained that his brothers and other family members were ashamed of his deaf daughter and had as little to do with her as possible. Contact with other parents of deaf or hard of hearing children can help a lot. Parents find being able to share their experiences and hopes with other parents in the same position valuable and reassuring. In this study, however, few parents had access to a resource of this kind. Though some active parents had recently established a support group, not all parents could benefit from it. In particular, the lives of many carers (especially single mothers) simply do not allow them the time or opportunity to participate.

In many ways, of course, the parents and grandparents we spoke to are no different from parents in other studies in other countries. Many – poor and rich alike – hope that their child will be able to continue its education and gain a qualification that will lead to secure work and a degree of independence. Their anxieties too are similar to those of parents everywhere. Some were worried that their child would be bullied (or worse) at school. One or two with girls entering adolescence were worried about the behaviour of older boys whom their daughters might meet. Some thought teachers needed to be better educated regarding working with children with disabilities, whilst others worried that that their son or daughter would not find a partner. The major obstacle in their child’s way, many agreed, were discriminatory attitudes: people staring or making jokes in public, as well as the attitudes of employers. Some referred to the fact that children in their neighbourhood or family did not want to play with their child. Some were critical of what ‘inclusion’ had come to mean in practice; that one or two children with special needs attending a school does not make it ‘inclusive’; real adaptations are needed for a school to become properly inclusive. None of this is unique to Ecuador.

What of sign language and participation in the Deaf community? Acquisition of sign language, participation in the Deaf community, and identifying as Deaf (rather than hearing impaired) can provide a deaf child with important cognitive and affective benefits. Though cochlear implantation of deaf children is becoming increasingly common in much of the world, this need not exclude the use of sign language: some deaf children are brought up bilingually. We found nothing like this in Cuenca. The children who were attending (or had previously attended) a signing school seemed mostly to be there because there were no other options available to them. The idea that a deaf child might gain psychological strength and self-confidence, a sense of belonging, from participation in the Deaf community seemed
unknown to the parents we interviewed. This is partly a matter of perception and partly a matter of Ecuadorian reality. Few deaf people have had the benefit of higher education and the Deaf community lacks the resources to attract and interest hearing parents. There is a great need for measures to facilitate the entry of deaf students into higher education: educating the future leaders of this community.

What now? Together with Lourdes Huiracocha, Liliana Brito and my other colleagues in Cuenca, I am turning our findings into articles that will, hopefully, appear in academic journals. This is not enough, however. We want our study to play a role in public discussions and in policy. If all goes according to plan, there will also be an article (in Spanish) in a local newspaper, as well as a report (in Ecuadorian Sign Language, LSE) for the Deaf community. For my part, I hope to return to Ecuador next year, to continue the work we started.

SUNG KUK KANG: A JOURNEY THROUGH DANCE AND PERFORMANCE
Zoe Goldstein

Sung Kuk Kang is the one and only disabled professional performer and dancer in Korea. He presents about thirty performances a year, mostly in his home country, though in recent years he has been travelling and working much more abroad. His first international invitation was to the ‘Sixth Sense in Performance Arts Festival’ in Taiwan in 2012 – a festival that highlights the work of artists and performers with disabilities – and he has also performed in Germany, Russia, Switzerland, Hong Kong, the UK and Australia. In 2013, Sung Kuk began his career as a director and choreographer for his own physical theatre/dance company in Seoul, directing for the first time non-disabled professional dancers. In addition to being a dancer, he is also a web designer, documentary filmmaker, film actor, visual artist, and the subject of a documentary film by independent Korean filmmaker Hyesung Han (currently in development). Sung Kuk was recently in Berlin, which is where I had the opportunity to meet him and find out more about his work and motivations.¹

Sung Kuk Kang, who has cerebral palsy, has physical and speech limitations, which means that he often finds it easier to do things with his feet or mouth than to use his hands. When using his computer, for instance, he types with his feet. He studied web design, advertising and public relations at university before he went

¹ Many thanks to Hyesung Han for acting as translator during our meeting.
into performing. Though it is rare for people with disabilities in Korea to go to university, he attended the sole university in the country with a dedicated programme for disabled people – the Korea National College of Rehabilitation and Welfare in Pyeongtaek, just outside of Seoul – where he studied with a small group of other people with disabilities as well as able-bodied students.

In 2003, his life and focus changed radically when he joined a workshop for art physical therapy, with a mixed group of people with and without disabilities, organised as part of the ‘Korea Experimental Arts Festival’ in Seoul. The director of the festival, Kim Baek-Ki, is a famous performer in Korea and internationally. During this workshop he had his first experiences with performance/dance, and discovered that dancing in front of others brought him a feeling that he loved – and he wanted more.

He decided to follow this path further, and in 2006 started to dance professionally. He approached a friend of his, Kim Nam Jin – a dancer/ choreographer who has performed with renowned companies in both Korea and Europe, before starting his own company ‘Dance Theatre Chang’ in Korea – and suggested that they collaborate. Their resulting duet, ‘Brother’, sheds light on an often hidden topic, especially in Korea, namely that of disability and shame. The piece tells the story of an able-bodied older brother and his disabled little brother, and describes the love and pain of their relationship, and the suffering they experience – and that the older brother inflicts on his ‘shameful’ younger brother – due to stereotypes, prejudice, and discrimination. ‘Brother’ won the dance award in the ‘CJ YOUNG festival’ in Seoul, and they have taken it to many international festivals, including in Hong Kong, Switzerland, Belgium, Germany, France, and the Proteatr Festival in Russia in 2012, where they won the Grand Prize.

Reflecting on the first times that he performed publicly, Sung Kuk recalls that the reaction of the audience was primarily focused on his disability and not on the work itself. He says it is getting a little better now, and that this attitude is slowly changing after so many years of appearing and performing, though people still focus most on his disability. He feels that attitudes are perhaps a little more open when he is abroad than in Korea.

In general, it is very difficult in Korea for people with disabilities to perform, and there is little general awareness of disability issues. It is difficult for them to go out, to work, to be active members of society, and as a result, Sung Kuk reflects that they themselves often think that they are simply unable to do anything. People with disabilities do come to his performances and their response is very positive, though he has the feeling that it has not yet really changed anything, and that they do not necessarily start to think differently about who they are and what they can do. He has already led two dance/performance workshops with people with disabilities, and would like to do more, but they are difficult to organise because people in Korea are still quite closed to the idea.

This negative attitude towards people with disabilities is something that Sung Kuk is continually trying to challenge through his work. Nevertheless, he still mostly works with non-disabled dancers. Three years ago, for instance, the Berlin-based Japanese Butoh dancer and performer Yuko Kaseki came to Korea to perform, and inquired about dancers with whom she could collaborate. Yuko has worked with disabled dancers in Berlin – for example, in a piece earlier this year entitled ‘Surnature: Anatomie du Erdboden’, featuring independent
performer/author Roland Walter, Yuko Kaseki and a high-tech wheelchair – and this is how she was introduced to Sung Kuk. They have performed together several times since.

Their most recent collaboration was in Berlin this July. Sung Kuk, Yuko Kaseki and Russian Butoh dancer Valentin Tszin made a group show of both solo performances and a trio in the Dock 11 theatre, and then collectively led a four-day experimental Butoh and ‘radical dance’ workshop (I am very fortunate to have attended this workshop, and this is how I was introduced to Sung Kuk). Over the four days, the three dancers – who all have incredibly different physicalities and therefore bring their own very particular approach to dance and physical performance – led the group in a series of exercises and improvisational frameworks. The process and results of the workshop were incredibly inspiring. Sung Kuk in particular focused on a series of performative exercises drawing attention away from the hands and onto creative ways of utilising and performing with different parts of the body, from the head to the foot.

His final performance in Berlin before departing for Seoul was an improvised duet with Yuko Kaseki in the gallery/performance space of the Asia Contemporary Art Platform NON BERLIN. The performance began outside, in the midst of a summer thunderstorm, with Sung Kuk, paint brush in mouth, writing a text in large white Korean characters on the wet street, while Yuko, carrying a paint bucket, performed alongside. Gradually the two came together and danced with one another, before slowly making their way into and then through the gallery, playing with the space and objects in the room, and reacting to and interacting with the audience.

The performance was followed by a discussion, during which Sung Kuk translated the text he had written on the street. The first phrase read “I am the only normal person, you are all abnormal”, while the second text was a series of questions: “What do you want? Where are you going? What is your path?” With the first
statement, Sung Kuk explained that while he may have a clearly visible physical disability that many would see as an abnormality, he questions the so-called normality of all those who go around thinking of themselves as able-bodied. Of the three questions, he elaborated that these are questions he asks himself on a daily basis, especially in terms of his performances and his creative trajectory.

One member of the audience asked Sung Kuk why, given the physical demands and expectations – and often strict standards – placed on (professional) dancers, he has chosen dance as his medium of expression. Sung Kuk responded that indeed, the first four or five years were very stressful, because he was constantly frustrated that he could not do the movements that other able-bodied dancers could do. It was not until he met a dancer/choreographer who highlighted to him how unique and special his own way of moving is, and who urged him to stop trying to imitate others, that he started to embrace and work with his own physicality. His way of moving is indeed inimitable; he has tremendous strength and agility, and his movement and rhythm are determined by his own unique physicality, which he plays and experiments with. When he performs with other dancers like Yuko Kaseki, most of whom are not disabled, the physical language and expression in such collaborations is always one of dynamic and energetic exchange, which does not dwell on the fact that he has ‘limitations’ in terms of movement – all bodies have limits, after all! – but plays with each performers’ potentialities and borders, and challenges audiences’ preconceived notions and expectations.

At the age of thirty-five, he feels driven to dance and perform now as much as possible before he gets older and starts to have problems with his body. Nevertheless, his inspiration – which he draws from what he sees and hears around him, from what he senses and experiences – is a resource without limits. Reflecting on what he gets out of performing, and why he feels compelled to dance, he stresses that more important and meaningful for him than the end result – the performance itself – is the process of creation, the journey, the collaborations and experiences he has along the way. It is important, he stresses, for everyone to find their own way. Plus, he adds with a grin, the buzz he gets from performing in front of others, the applause, is what makes him keep going. And for this he is still hungry.

You can find out more about Sung Kuk Kang through his Facebook page: facebook.com/koreaingan, or you can contact him at: koreaingan@empas.com.

IS STEM CELL THERAPY A LIFESAVER? PATIENTS’ EXPERIENCES OF AND VIEWS ON STEM CELL THERAPY IN CHINA

Suli Sui

Over the last decade, many companies and hospitals in China have cooperated to offer stem cell therapy, without the Ministry of Health’s (MOH) official permission. In 2009, there were around 100 stem cell companies and 400 hospitals/medical institutions using stem cell transplantation as clinical therapy. Stem cell therapy (SCT) was indeed thriving in China,

2 This article has benefited from research support provided by the ESRC (RES-062-23-2990).

3 The Ministry of Health changed its name to the National Health and Family Planning Commission of the People’s Republic of China in March 2013. Since the rules mentioned in this paper were enacted before the MOH was changed to the NHFPC, this paper still uses the name MOH.
which also attracted foreign patients, who became labelled ‘stem cell tourists’. Despite its prevalence, the use of STC was unorganised and unsystematic because of the lack of overall governance and supervision, a situation that was termed the ‘stem cell mess’ in China.

After the MOH enacted measures in January 2012 and three draft rules in March 2013 to rectify the situation of SCT, almost all of the hospitals that had previously been working with SCT ceased their activities. There are nevertheless several hospitals run by the military and armed police forces, as well as privately run hospitals, that still offer clinical SCT services to the public. In practice, as a new and advanced technology, SCT is seen as a very attractive option for patients suffering from as yet incurable medical conditions. In the past, when unregulated SCT was thriving in China, many patients treated it as a ‘lifesaving’ option, and were prepared to pay a high price to give it a try. This short paper presents the cases of three patients who undertook SCT. Their personal experiences and views offer an insight into the use of SCT in present-day China.

Case A: ‘The technology is not yet mature enough’

Patient L had been suffering from hemiplegia – severe weakness or paralysis of one side of the body, often caused by stroke – for four years when I spoke with him. Here is his experience of undertaking SCT:

My hemiplegia is the result of a brain haemorrhage. I undertook SCT in 2011 at the Beijing Armed Police Hospital. This armed police hospital has its own lab and has a National 863 research project. Nobody told me that the therapy is experimental. It is impossible that there is no charge for the therapy [i.e. that it would be provided free of charge], and there are so many patients who come and they are all eager for therapy. I registered in 2010, and waited on the list for nearly one year. It cost me around 50,000 RMB [Chinese Yuan Renminbi; approx. 6,000 Euros] for one course of treatment. The treatment was barely effective. My muscle tension increased a little, but this little improvement was already gone a few months after the therapy. I did not want more treatment. I know the technology is not mature enough. Anyway, I gave it a try, which maybe was a chance for me. I do not regret that. My opinion is that if you have money, you can have a try. Only take it as a try, and do not have too much confidence. But to be honest, I think it is better to wait for the development of the technology.

L is a young man and he told me that he had already gotten used to his present life situation. He had created a QQ group for people with nerve injuries. The group has around 330 members, most of whom are suffering from nerve injuries, and they encourage one another and exchange information on SCT.

The term ‘stem cell tourists’ was commonly used to express the phenomenon of SCT attracting foreign patients to China. See e.g. http://www.bioon.com/tren3600.shtml#ds/news/43, and http://news.163.com/10/0210/11/5V5HQPFO00011SM9.html.

The term ‘stem cell mess’ was commonly used to express the disordered situation of SCT. See e.g. http://finance.sina.com.cn/consume/puguangtai/20110429/2738977628.shtml, and http://health.sohu.com/20120507/n342536899_1.shtml.


863 project is the name of a national science development project in China. The project provides significant funds for advanced technology research.

QQ is a very popular software for online communication and is widely used in China.
Case B: ‘I felt like a lab rat’

Patient Z, who has diabetes, comes from Wuxi, Jiangsu province. He undertook SCT in 2010 in 455 Hospital, an army hospital in Shanghai. 455 Hospital is also a Medical Transformation Base of the National Stem Cell Engineering Research Centre. In China, the army is called ‘the army made up of the sons of people (子弟兵)’. Because of this, army hospitals are usually regarded as more reliable, and people may trust them more than other hospitals. Here is what Z had to say about his experience with SCT:

I found the information on SCT from the internet. You know a person with a serious illness would like try anything to be cured (有病乱投医). Shanghai is a big city, 455 is a big hospital. So, I came there for therapy. In the hospital, I was told that stem cells have a magical effect, and more than 90% of diabetes patients can be cured by SCT. I trusted it and I really hoped I could be cured. I spent 80,000 RMB [approx. 9,500 Euros]. However, there was no effect, but some harm instead. Later, I got to know little by little that SCT technology is still in the research stage. I feel like I was a ‘lab rat’ for a trial. SCT is cheating, the hospital does not save people but harms people. I posted my experience on the internet. I would like more people know the truth so they won’t be cheated like me. One CCTV [China Central Television] reporter interviewed me, and later a CCTV program disclosed the truth about SCT to the public. The hospital returned my 80,000 RMB.

Even though Z got his money back, he became a campaigner opposing the ‘lie’ of SCT. He called himself a ‘fighter’.

Before 2012, although the practice of SCT was flourishing in China, almost all patients with whom I spoke had had similar disappointing experiences. Being charged a high price for SCT, but without seeing any positive effects, the patients I interviewed were usually very angry about their experience, and most felt that they had been cheated. Here are some of the patients’ own words:

The hospital is the biggest liar, murder for money.

Whoever undertakes SCT is being cheated! I paid 30,000 RMB [approx. 3,500 Euros], but my disease is now more serious, I nearly died after treatment.

Patients want to be cured at all costs, but the doctors are so bad, they only want to earn money!

What the doctor told sounds as sweet as a song (说的比唱的好), but what is the effect? Cheating!

Case C: ‘I believe in SCT’

Although there was a lot of blame and criticism of SCT among the patients in my research, during my fieldwork I did meet one who was satisfied with the SCT she had undertaken. Hers was the only ‘successful’ case I came across.

Patient Q is a lady with severe paraplegia who lives in Qingdao city. Her home is close to Chengyang Hospital, which has an SCT centre that attracts many foreign patients. Despite this, she visited several hospitals in different cities in China, and finally chose the Shandong Red Cross
Intervention Hospital, a non-governmental hospital in Jinan run by the Red Cross. She told me her experience with SCT:

I live in Qingdao Chengyang, certainly I know the Chengyang Hospital and know that SCT centre. But I do not trust it. I undertook SCT at the Red Cross Hospital in Jinan in 2011. One course of treatment is around 50,000 RMB [approx. 6,000 Euros]. I undertook four courses, which cost more than 200,000 RMB [approx 23,700 Euros], but I think the money is worthwhile. Before therapy, I had no sensation in the lower part of my body. Now, I can feel when I need to go to the toilet, I can sit, and I even can walk with a leg brace. I am very happy with the result. I think I am lucky to reach this condition. It is great for me. I do not care about others’ words; for me, I believe in SCT.

I contacted the Red Cross hospital that Q attended and spoke with the doctor in charge of SCT. The doctor told me:

Our hospital has more than ten years of experience of stem cell therapy, and nearly 90 percent of patients have more or less a [positive] effect. The effect gives patients hope and confidence. The hospital cooperates with Pennsylvania University, and gets technology support from the university. The experts from the US offer training courses for us. Our hospital already has many ‘successful’ cases and never any injuries. After treatment, most of the patients’ conditions and life quality are improved.

Given patient Q’s positive experience, the doctor’s statement above may seem to be somewhat reliable. Nevertheless, given the negative experiences of all of the other patients with whom I spoke, as well as the lack of standard governance on SCT, its impact on patients’ wellbeing, and its high cost, many SCT practices in hospitals arguably violate patient rights to some extent, and destroy public trust in the technology, as well as the hospitals and doctors conducting it.

Even though the MOH enacted new rules and regulations in 2012/2013 governing SCT, most patients nevertheless still did not know about them. They had no idea, for instance, that SCT is still in the research trial phase; furthermore, they did not seem to care particularly about the trials. What they cared about is when the ‘real’ stem cell therapy would be approved. When would this advanced technology be used in clinics and be able to save life?

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DIGITAL DEVICES FOR KNOWING THE SELF: THE LATEST TRENDS IN SELF-TRACKING AND THEIR IMPLICATIONS

Gabija Didžiokaitė

The terms self-tracking, Quantified Self, and personal informatics all refer to the same phenomenon of using new digital technologies to monitor various aspects of one’s life and body. As has been mentioned time and again, self-tracking in itself is not a new phenomenon. People have long kept diaries, not only to record their mood and activities, but also their weight,
temperature, blood pressure, food intake, and other consumption patterns. Furthermore, not so long ago, many medical measuring devices became digitalised, and thus able to store data from previous measurements, enabling users to keep track of, say, their blood pressure over several weeks. So why has self-tracking attracted so much recent attention in the media and increasingly academia?

Well, first, the novelty of today’s self-tracking practices is related to the devices being used for the purpose. These are largely wearable computers; that is, devices that can be attached to the body, which then track several aspects of bodily performance: usually activity levels, number of steps taken, distance walked, calories burnt, calories consumed (this usually requires users to input information about food consumption), and patterns and quality of sleep. Some of the devices are adjusted to specific sports like running or swimming, and measure aspects of performance that those practising these activities find useful. Moreover, a lot of this tracking can be done using smartphones, simply by installing the required apps. So for many, the need for new devices is minimal and starting to track oneself is quite easy. Second, those who are engaging in this practice have assembled themselves into a Quantified Self community, active at both the local and international level, which works closely with the developers of self-tracking technologies. Third, various ethical and social questions about self-tracking and its implications are being raised. So to provide a better idea about the phenomenon and the buzz surrounding it, in the following paragraphs I will look into these three points in more detail.

Even if we are at the beginning of the new digital self-tracking movement, there are already numerous devices and many smartphone apps that are designed to help us collect data about our performance and bodily functions, and many more new devices are being introduced each year. Typically, such devices take one of the following three forms: wristwatches, wristbands and small attachable gadgets. As there are far too many devices to cover in this short piece, I will limit myself to exploring some of the most popular.

The most popular self-tracking device from the wristwatch group seems to be Basis. As with other self-tracking device brands, Basis offers several kinds of wristwatch trackers, though they all do essentially the same thing. Basis seems to be special not only among the wristwatch group, but also among self-tracking devices in general, because, in addition to monitoring motion (which also permits the monitoring of sleep), it also senses temperature and heart rate. The screen on the watch displays the current information, and connecting Basis to a computer allows the wearer to keep track of their performance over time. So far, it seems to be only available in the US.

Three devices can be distinguished as the most popular among the wristbands – Jawbone,
FitBit, and Nike+ FuelBand – all of which track activity and sleep. For activity, the real focus, as with many other devices, is on step-based activities, and though the tracking of other kinds of workout/activity is possible, many have talked about these and similar self-tracking devices as simply advanced pedometers. In addition to these features, the Nike+ FuelBand has an LED light display that shows NikeFuel – activity measuring points invented by Nike. What exactly is being measured by these points, and how, is not clear, but they seem to offer another way of visualising personal activity levels. As with Basis, these devices can connect to a computer, allowing the user to see patterns in their performance and sleep, as well as to input data about food consumption and mood (FitBit and Jawbone only).

In the third group, Misfit Shine is a sleek and small activity tracker that can be either clasped onto clothes or worn on a wristband. Again, this device is intended to measure activity and sleep, but tops the other devices by also allowing the user to track such activities as cycling, which wrist-based trackers cannot measure successfully, and also by being completely waterproof. Another clip-on device, MOOV, though it is not due to be launched until later in 2014, already promises to be a prominent tool, as it will not only track various activities but will also give real-time advice on how to improve performance in five activities – running, cycling, swimming, cardio boxing and weight training – with even more activities promised in the future.

All of these wearable self-tracking devices and apps have increasing numbers of users, many of whom associate themselves with Quantified Self - ‘an international collaboration of users and makers of self-tracking tools’ [1]. The user community that is served by this collaboration organises local ‘meet-ups’ (meetings based on the Meet-up internet platform) as well as international conferences. A key feature of the meet-ups is a ‘show and tell’ element, where users present the self-tracking technologies that they are using or working on and talk about their experiences with them. The Quantified Self website also has a forum, which allows those involved in self-tracking to share their ideas, concerns, and questions online on matters regarding diet, sleep, mood, activity, and their tracking. As demonstrated by the popularity of this year’s Quantified Self Europe Conference (May 10-11) in Amsterdam, which had a capacity of 400, and by the fact that the ‘meet-up’ group in London has around 1,500 members (some cities in the US boast even more), it is safe to say not only that self-tracking is quite popular, but also that is not necessarily an individual practice.

But what can we make of all this abundance of self-tracking devices and users? What does it signify and what concerns may be raised? On the one hand, self-tracking can be seen as putting more power into patients’ hands: with devices measuring heart rate and temperature, we are able to better know and evaluate certain aspects of our health without relying on ‘professionals’. There is also the idea that measuring activity and sleep levels will help people to improve their health. On the other hand, all of the existing self-tracking devices base their measurements and evaluations on statistical ‘normalcy’. This means that there will be people who are and feel healthy despite being above or beyond the ‘normal’ range as defined by these devices. Measuring personal performance in relation to such numbers can therefore both raise unfounded concerns if the numbers are too high (or too low), even if the user feels subjectively well, as well as empower,
through users learning their own personal ‘normal’ levels.

Nevertheless, what all of this implies is that health is easily measurable and is entrenched in numbers, which is a daunting and limiting idea that seems to strip away all meaning from our own embodied perceptions of health. But even if we believe that relying on numbers is the best way to understand our health, the actual meaningfulness of the information provided by self-tracking devices is still questionable. Currently, self-tracking devices provide information about a few different aspects of health, but we have little or no understanding of how to interpret these numbers together [2]. Furthermore, in order to gain a rounded understanding of our health, we would need much more data, which would then be even more difficult to grasp.

Ideas are currently being raised about the possibility of using all of this personal data together as so-called ‘big data’. Gathering the data of thousands of users’ health patterns could be helpful in improving health provision; for example, collecting big data on heart rate could help predict cardiac events in advance [3]. This seems like a beautiful idea: an individual, without making any additional effort, can help to improve the wellbeing of many. However, the focus of self-tracking devices, which is on individual metrics, rather strengthens the idea of individual responsibility for personal health in a way that dangerously takes focus away from environmental accountability in health and disease [4]. Thus, though it is argued that self-tracking may help many to better understand themselves, it is not clear what kind of knowledge they will actually gain and how this will affect understandings of health and even of the self.

It is hard to judge whether the popularity of self-tracking will increase, as not everyone is interested in knowing how many steps they made in a day or how many times they woke up during the night. Nonetheless, as more sophisticated ways of self-tracking are on their way – for example, with such technologies as the promised Apple Healthbook [5] – even more questions about the implications of self-tracking will arise. Research providing a better understanding of what is happening now, at the beginning of the phenomenon, could therefore help to pave the way forward, and to find answers to both current and future questions raised by these new technologies and practices.

References

Gabija Didžiokaitė graduated from the University of Warwick with a BA in Sociology and is now finishing a Research Masters in Social Sciences (specialising in Medical Anthropology) at the University of Amsterdam. You can contact Gabija at: gabijamd@outlook.com.
OBITUARY
PROFESSOR JOHN PICKSTONE
Stuart Blume

John Pickstone died in February this year, suddenly and unexpectedly, at the age of 69. John was an historian of medicine and of science, whose broad interests ranged from detailed local studies of hospitals in the Manchester area to the general, of what he saw as the science-technology-medicine complex. His book on this latter theme, *Ways of Knowing*, has become a classic. For many years, John directed the Centre for the History of Science Technology & Medicine at Manchester University, as well as the Manchester Wellcome Unit for the History of Medicine. In 2002, he became a Wellcome Research Professor. Both personally and professionally, John was very supportive of Innovia. He was a member of the Scientific Advisory Board we set up when Innovia was established, and he participated in the conference we held at the Rockefeller Foundation’s Bellagio Center to launch it. A full obituary of John Pickstone, written by his colleague Professor Michael Worboys, appeared in The Guardian newspaper in February: http://www.theguardian.com/science/2014/feb/23/john-pickstone.

ANNOUNCEMENTS

International Conference: *6th World congress on mental Health and Deafness - Pathways to Rights*  
16 - 19 September 2014  
Riddel Hall, Queen’s University Belfast, Northern Ireland

The congress features a specific theme, which is the relationship between human rights and mental health of deaf people. We invite delegates from all countries who have an interest in the subject and the theme. We believe that the stronger the representation, the more likely it will be that the conference will be able to influence policy-makers and help to improve lives. For full programme and venue details and to register, please see: www.wcmhd2014.org and http://www.bda.org.uk/Events/158.

International conference: *Sexual and reproductive health and rights today and tomorrow - ICRH celebrates 20 years of SRHR research, training and advocacy*  
4 - 5 December 2014  
Ghent, Belgium

On the occasion of its 20th anniversary, ICRH organizes a two-day international conference. The conference will focus on the state of the art and upcoming challenges in sexual and reproductive health worldwide. The full program will be available from September on, and at that time also the registrations will be opened. For more information, please contact: icrhconference2014@ugent.be.
Call for Authors: The SAGE Encyclopedia of Pharmacology and Society

We are inviting academic editorial contributors to The SAGE Encyclopedia of Pharmacology and Society, a new 4-volume reference to be published by SAGE Reference. The General Editor, who will be reviewing each submission to the project, is Dr. Sarah E. Boslaugh, Kennesaw State University.

We plan an encyclopedia that will explore socioeconomic, business and consumer, and legal and ethical issues of the pharmaceutical industry in contemporary American and international societies. The list of available articles is already prepared, from which you can select topics that best fit your expertise and interests. Additionally, Submission Guidelines will be provided that detail article specifications.

If you would like to contribute with The SAGE Encyclopedia of Pharmacology and Society, please provide your CV or a brief summary of your academic/publishing credentials in related disciplines. Write to Joseph K. Golson at: pharmacology@golsonmedia.com.

Call for Contributions: Anthropology in Action

Special Issue on the Impact of Anthropology

Anthropology in Action is an international peer-reviewed journal publishing articles, commentaries, research reports, and book reviews in applied anthropology. Following the recent Research Excellence Framework Exercise in the UK, which introduced formal assessment of 'research impact', it is timely to reflect on the engagement of anthropology with public policy and practice and how it makes an impact on these spheres.

We invite submissions of articles and comment or debate pieces or other contributions reflecting on the issue of 'impact' including questions such as: how do we define and measure impact? How do anthropologists engage with public policy and discourse in order to make an impact? Contributions are welcome from any country.

The closing date for submissions to the special issue will be 30th September 2014. However, articles and commentaries on this theme are always welcomed, so contributions submitted later will also be considered for publication.

For more information, please contact Dr Christine McCourt, Editor, Anthropology in Action, Professor of Maternal & Child Health, School of Health Sciences, City University London, www.journals.berghahnbooks.com/aia/ and https://www.facebook.com/pages/Anthropology-in-Action/1429954747245407?ref=hl.

PhD position, University of Oslo, Norway

We are seeking a PhD fellow to carry out a sub-study within a larger interdisciplinary research project that will explore the role of international NGOs in the transfer of maternal health policy between global and local levels in Malawi. The project is funded by the Research Council of Norway’s Globvac programme and is led by the Centre for Development and Environment at the University of Oslo, in collaboration with the Chancellor College in Malawi.

The doctoral research fellow will conduct one of the project’s sub-studies, a local-level ethnographic study in Malawi, focusing on the interconnections and tensions between local and global ideas about maternal and reproductive health and how international NGO and policy discourses are shaping such ideas. There is scope for the applicant to develop both the theoretical and methodological content of this sub-study.
The selected candidate will have his/her place of work at SUM, but will – as a condition of being granted the fellowship – follow the PhD training programme at the faculty level.

For more information about how to apply, please see:

Renée C. Fox’s new book: ‘Doctors Without Borders: Humanitarian Quests, Impossible Dreams of Médecins Sans Frontières’

“Pioneering medical sociologist Renée C. Fox spent nearly twenty years conducting extensive ethnographic research within Médecins Sans Frontières. […] With unprecedented access, Fox attended meetings and observed doctors and other workers in the field. […] The core of the book is centered on her observations in the field of MSF’s efforts to combat a rampant epidemic of HIV/AIDS in postapartheid South Africa and the organization’s response to two challenges in postsocialist Russia: an enormous surge in homelessness on the streets of Moscow and a massive epidemic of tuberculosis in the penal colonies of Siberia. […] Enriched by vivid photographs of MSF operations and by ironic, self-critical cartoons drawn by a member of the Communications Department of MSF France, Doctors Without Borders highlights the bold mission of the renowned international humanitarian organization even as it demonstrates the intrinsic dilemmas of humanitarian action.” [Taken from http://www.doctorswithoutborders.org/doctors-without-borders-humanitarian-quests-impossible-dreams-médecins-sans-frontières]

Renée C. Fox is the Annenberg Professor Emerita of the Social Sciences at the University of Pennsylvania. She is author of Experiment Perilous: Physicians and Patients Facing the Unknown, In the Belgian Château: The Spirit and Culture of a European Society in an Age of Change, and In the Field: A Sociologist’s Journey and coauthor of The Courage to Fail: A Social View of Organ Transplants and Dialysis and Observing Bioethics.