Exploring the educational value of digital health platforms: Insights from MedicineAfrica and Care Opinion

University of Sussex Business School
Monday 16 September 2019

Organisers:
Drs. Dimitra Petrakaki and Petros Chamakiotis

Funder:
Foundation for the Sociology of Health & Illness

UNIVERSITY OF SUSSEX | BUSINESS SCHOOL

Given our interest in digital health, we have been leading and participating in research projects exploring how digital health can generate different types of value for different stakeholders. Our premise is that existing studies have taken a critical perspective toward the economic and technical function of digital health platforms, often at the expense of the social, and more specifically the educational, value they can create. There needs to be an appreciation that platforms vary in purpose and function and that there is scope for them to produce societal value that is orientated toward the improvement of healthcare delivery and clinical practice in developed and developing countries.

In light of the above, our workshop aimed to:

- Facilitate a debate around the organisation, function and effects of digital health platforms on quality of care, healthcare practice and delivery;
- Disseminate knowledge about the social value of digital health platforms; and
- Build a network with relevant representatives from the health platform economy, academics, healthcare professionals and students, with the aim of enhancing the prospects for future research collaboration.

The workshop took an interdisciplinary approach, bringing together researchers and practitioners from the fields of medicine, sociology, global and development studies and management studies to debate the above issues using a comparative approach. An interdisciplinary perspective is absolutely necessary given the multifaceted sociotechnical nature of digital health platforms.

Listening about different methodological choices adopted by researchers exploring digital health platforms from different perspectives enabled us to elicit points of convergence and divergence in the delivery of online health education (between developed and developing countries) and appreciate the contextual significance of the produced effects and values.

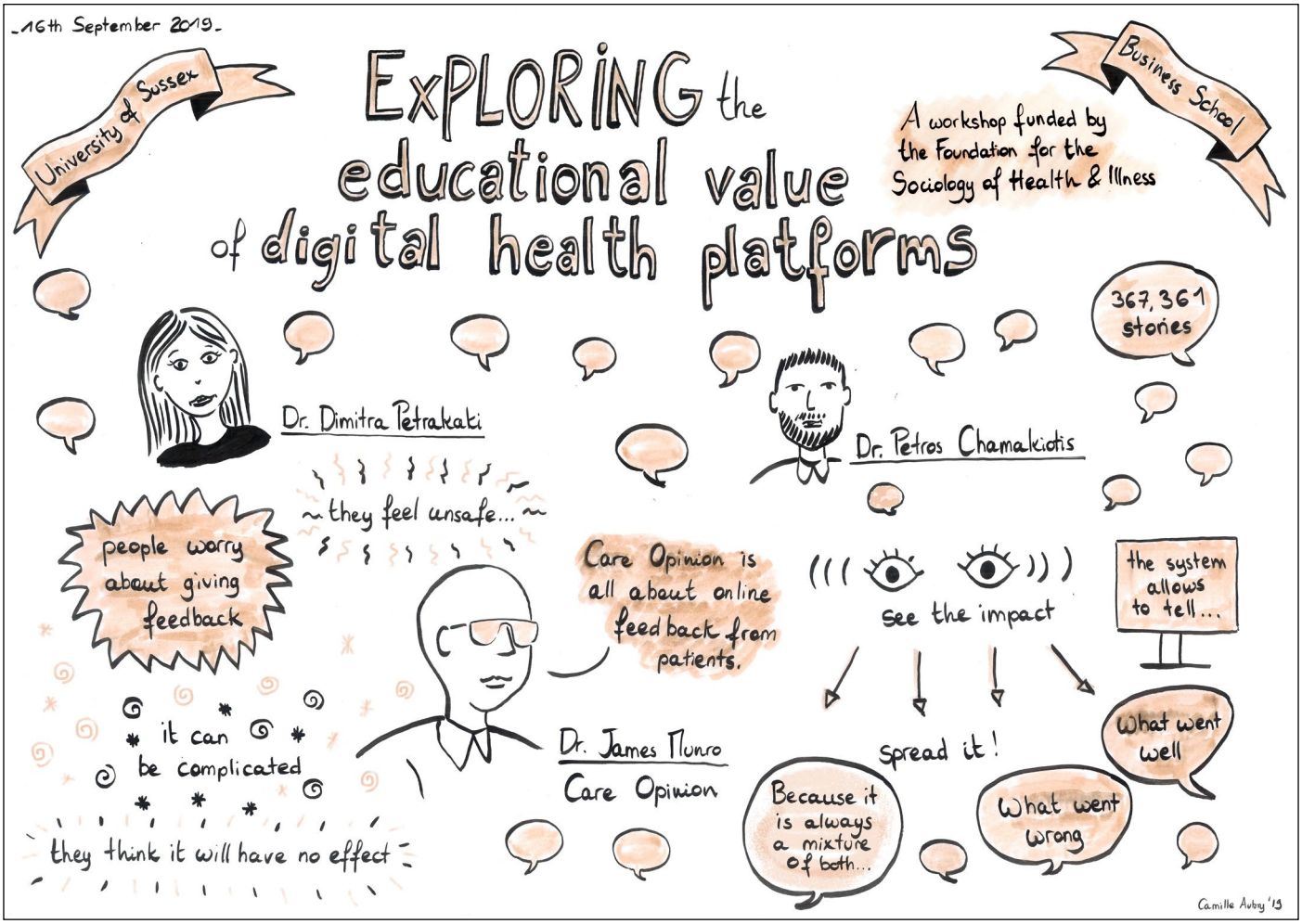
The workshop covered the following topics for discussion:

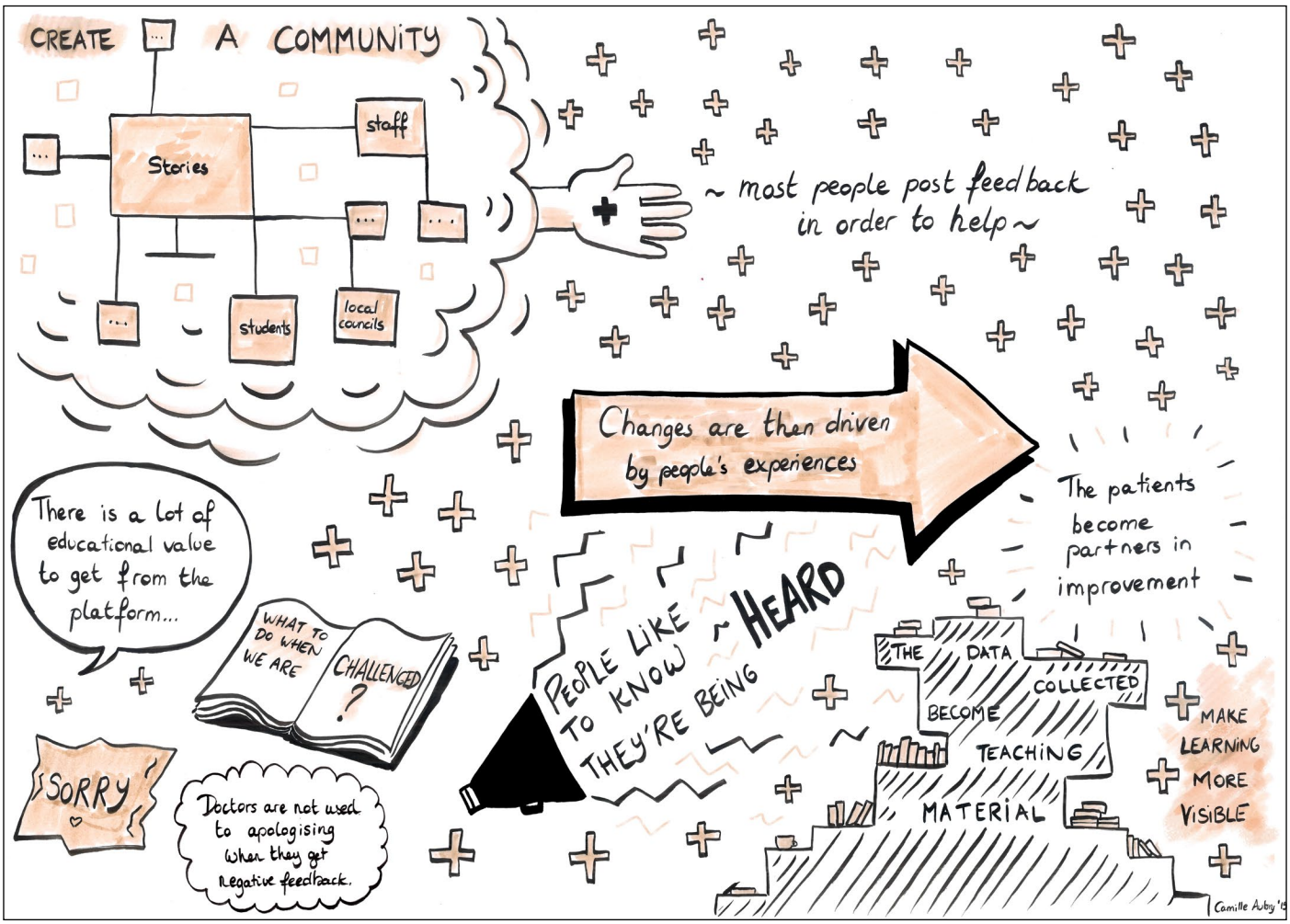
- Organisation and function of digital health platforms and of their purposes;
- Exploration and comparison of the different ways in which online health education is delivered; and
- Identification and discussion of a range of effects (on clinical practice and quality of care, health benefits, knowledge development, capacity building etc.) online health education delivered via platforms has on the recipient professionals, organisations, countries and societies at large.

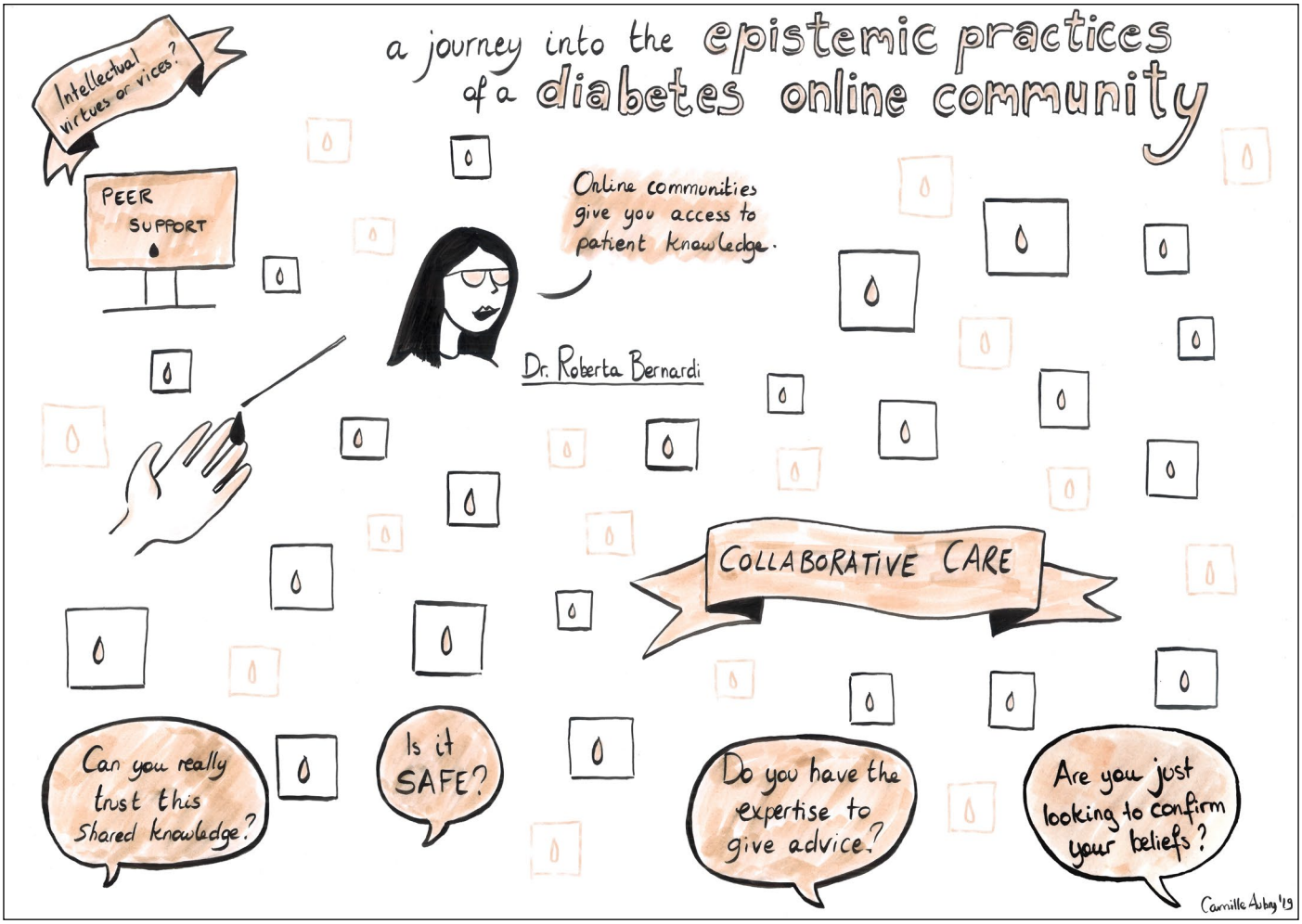
Presented next is the programme of the workshop, detailing the presentations given by our invited speakers, followed by a collection of illustrations developed by an experienced illustrator through live scribing.

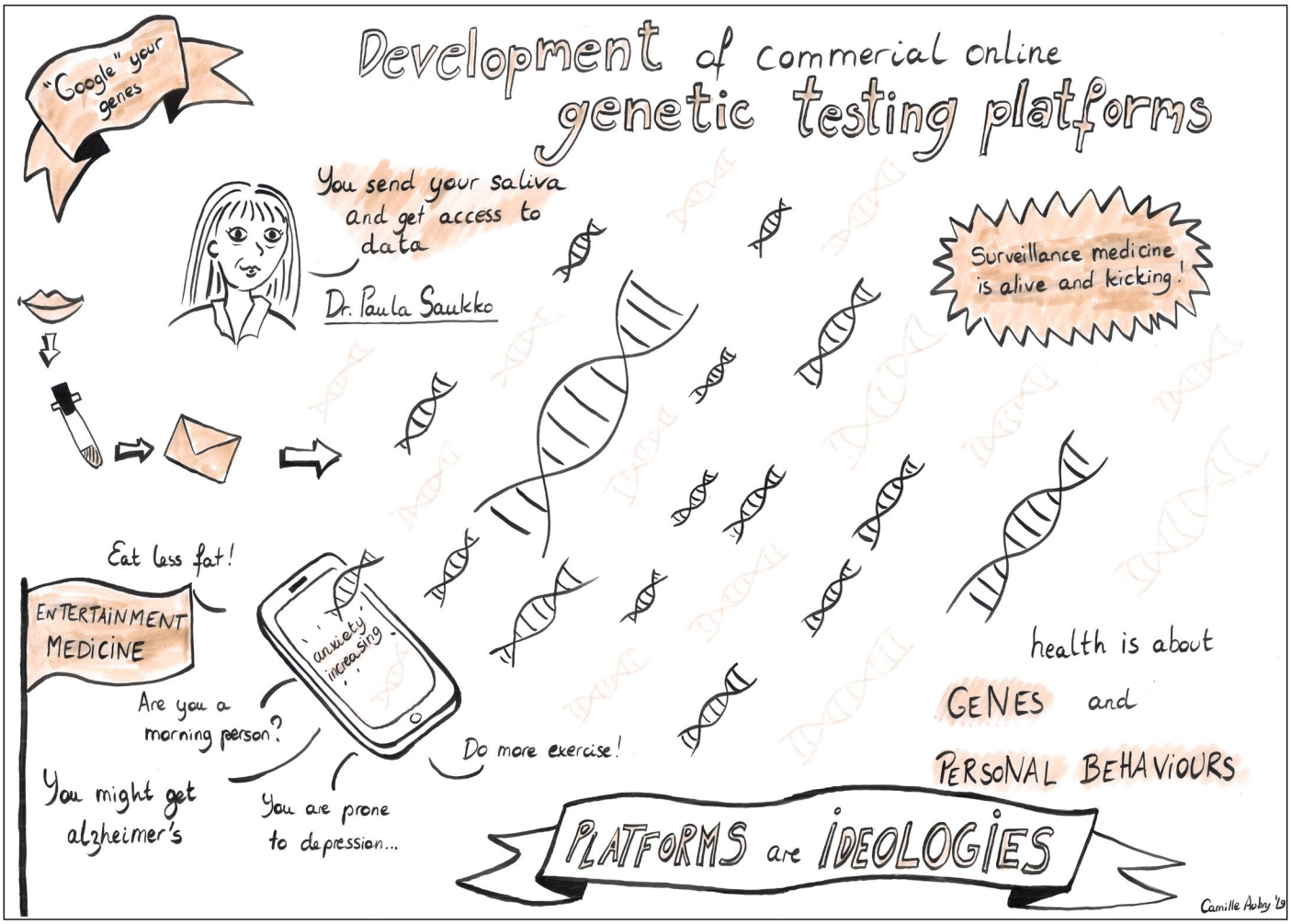
Programme

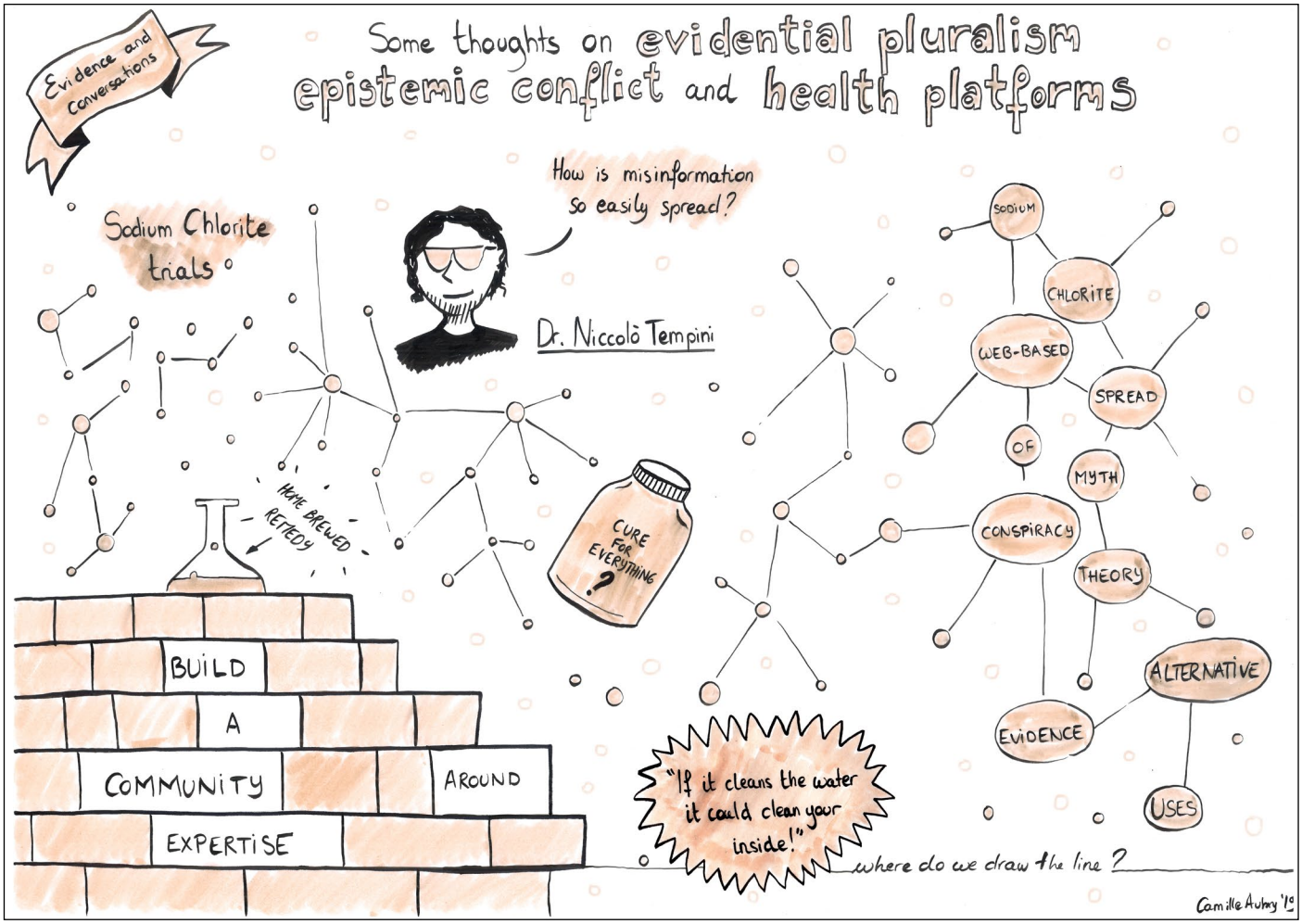
09:00 - 09:30	Arrival and introductions
09:30 - 10:30	'***Care Opinion: public online feedback for healthcare learning and change at scale***' **Dr. James Munro**, Care Opinion
10:30 - 11:00	Coffee break
11:00 - 11:30	'***Development of commercial online genetic testing platforms: From tacky stock images to big data medical cosmologies***' **Dr. Paula Saukko**, Loughborough University
11:30 - 12:00	'***Intellectual virtues or vices? A journey into the epistemic practices of a diabetes online community***' **Dr. Roberta Bernardi**, University of Bristol
12:00 - 12:30	'***Evidence and conversation: Some thoughts on evidential pluralism, epistemic conflict and health platforms***' **Dr. Niccolò Tempini**, University of Exeter
12:30 - 13:30	Lunch break
13:30 - 14:30	'***MedicineAfrica and the value of online education***' **Dr. Chris Tan**, MedicineAfrica
14:30 - 15:00	Coffee break
15:00 - 15:30	'***Is it stories or is it science? Constructing health knowledge on Twitter***' **Dr. Stefania Vicari**, The University of Sheffield
15:30 - 16:00	'***Transforming commitment into social value in online health communities: Our journey with MedicineAfrica***' **Dr. Petros Chamakiotis**, University of Sussex, & **Prof. Niki Panteli**, Royal Holloway University of London
16:00 - 17:00	Break-out session
17:00 - 17:30	Closure

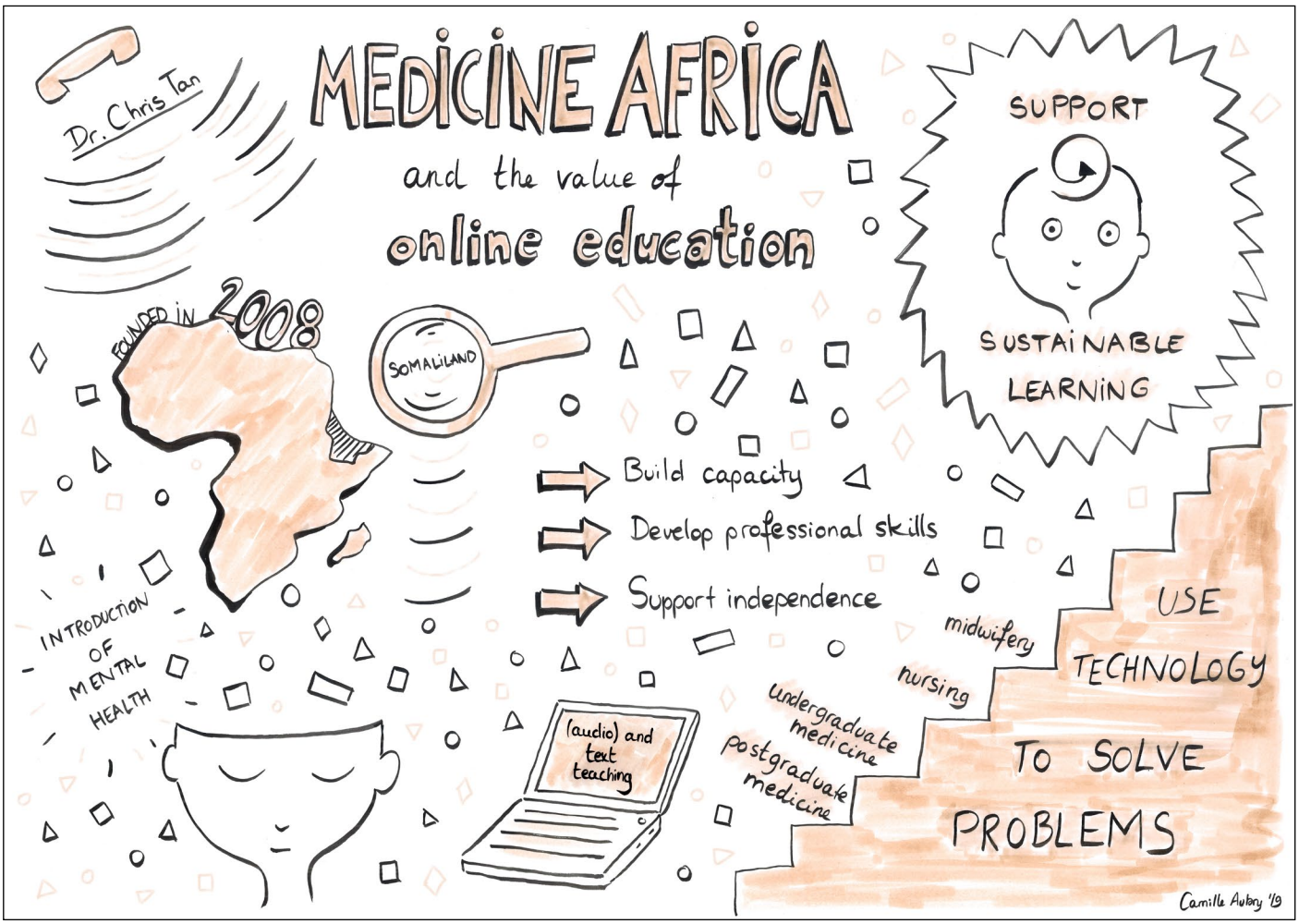

16th September 2019
University of Sussex
Business School
EXPLORING the educational value of digital health platforms
A workshop funded by the Foundation for the Sociology of Health & Illness
Dr. Dimitra Petrakaki
Dr. Petros Chamakiotis
367,361 stories
they feel unsafe...
people worry about giving feedback
Care Opinion is all about online feedback from patients.
see the impact
the system allows to tell...
it can be complicated
Dr. James Munro
Care Opinion
spread it!
What went well
What went wrong
Because it is always a mixture of both...
they think it will have no effect
Camille Aubry '19

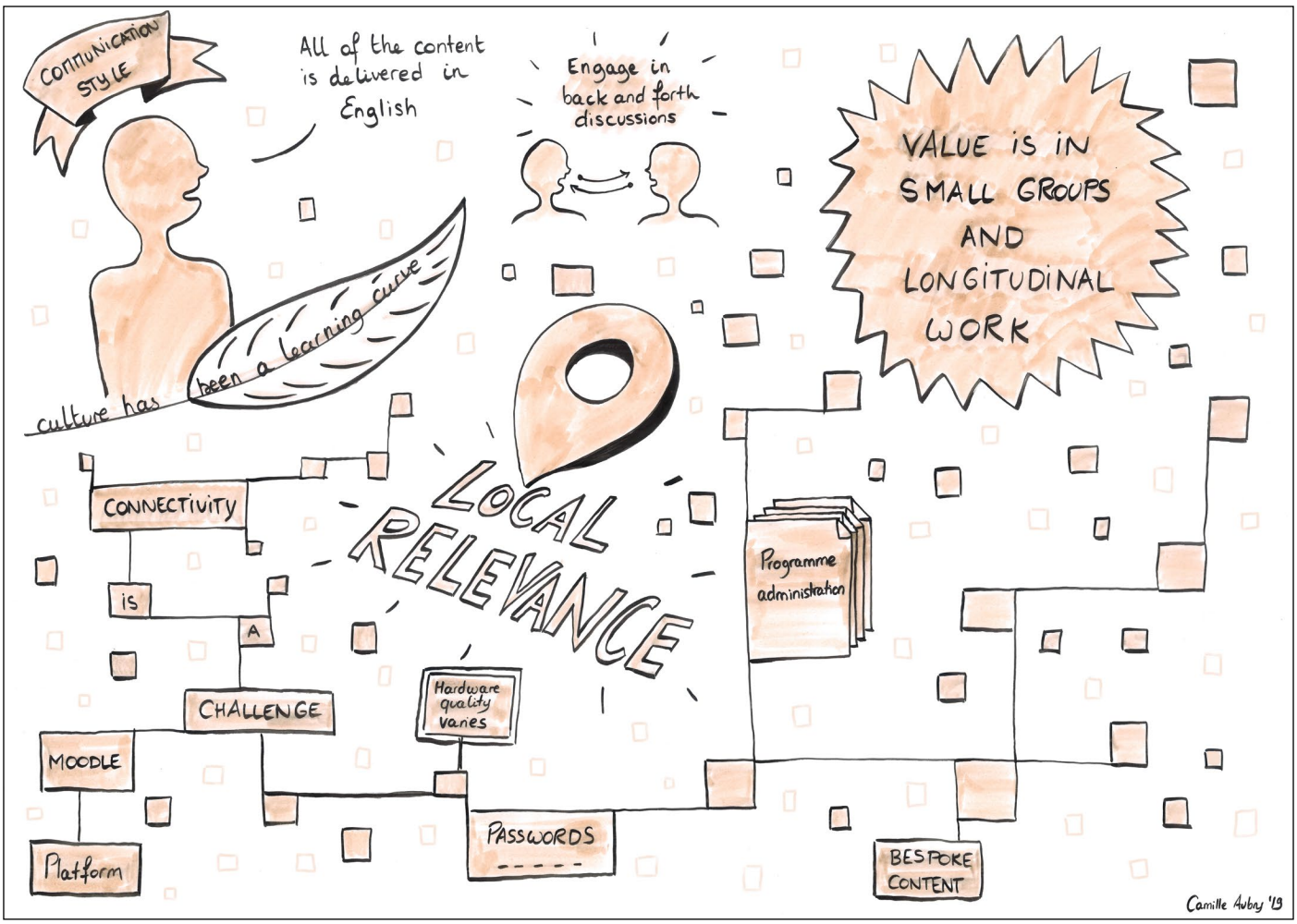

CREATE A COMMUNITY
Stories
staff
students
local councils
~ most people post feedback in order to help ~
Changes are then driven by people's experiences
The patients become partners in improvement
There is a lot of educational value to get from the platform...
WHAT TO DO WHEN WE ARE CHALLENGED?
PEOPLE LIKE TO KNOW THEY'RE BEING HEARD
THE DATA COLLECTED BECOME TEACHING MATERIAL
MAKE LEARNING MORE VISIBLE
SORRY
Doctors are not used to apologising when they get negative feedback.
Camille Aubry '19


a journey into the epistemic practices of a diabetes online community
Intellectual virtues or vices?
PEER SUPPORT
Online communities give you access to patient knowledge.
Dr. Roberta Bernardi
COLLABORATIVE CARE
Can you really trust this shared knowledge?
Is it SAFE?
Do you have the expertise to give advice?
Are you just looking to confirm your beliefs?
Camille Aubry '19

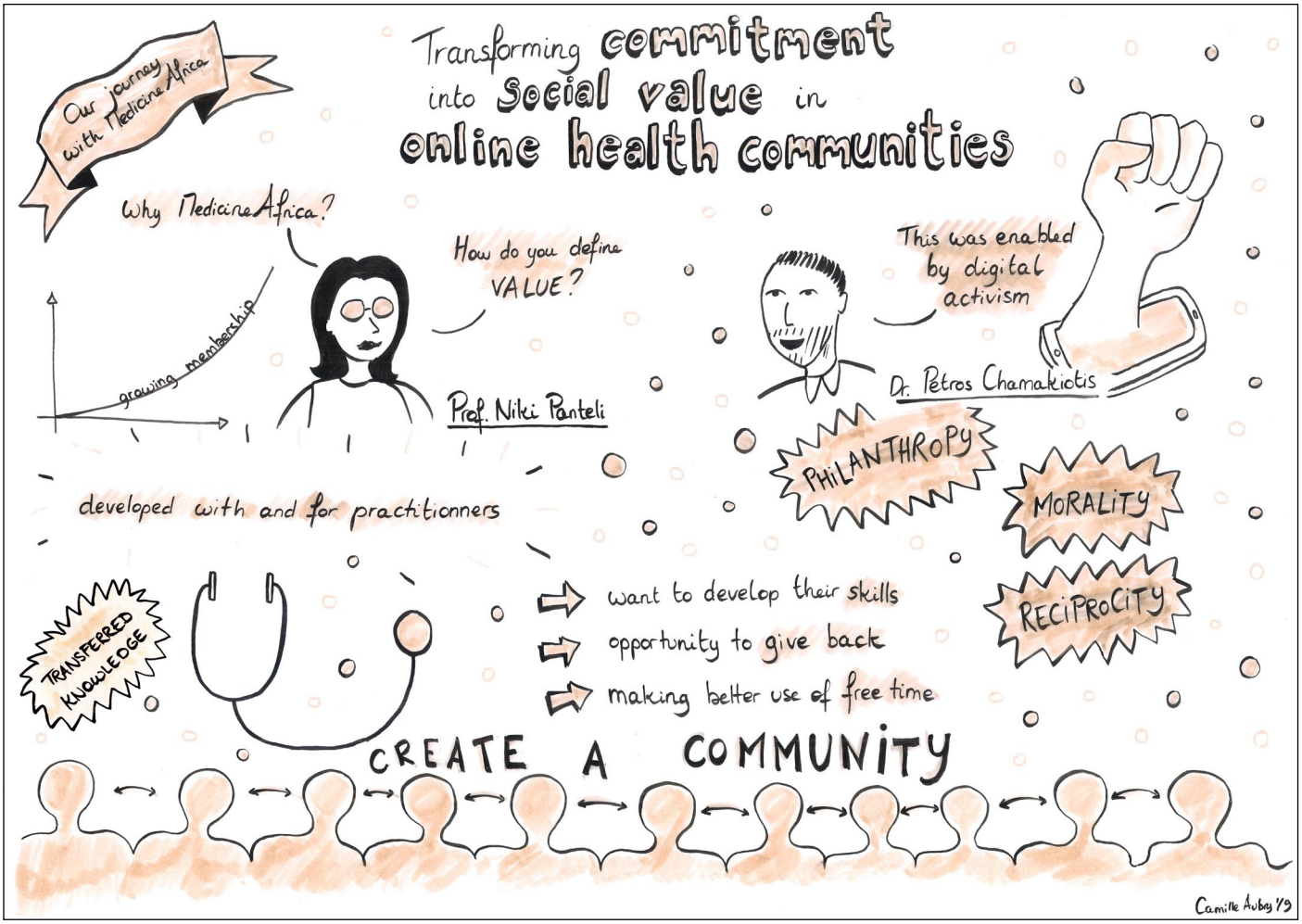

Development of commercial online genetic testing platforms
"Google" your genes
You send your saliva and get access to data
Dr. Paula Saukko
Surveillance medicine is alive and kicking!
Eat less fat!
ENTERTAINMENT MEDICINE
anxiety increasing
Are you a morning person?
You might get alzheimer's
You are prone to depression...
Do more exercise!
health is about GENES and PERSONAL BEHAVIOURS
PLATFORMS are IDEOLOGIES
Camille Aubry '19

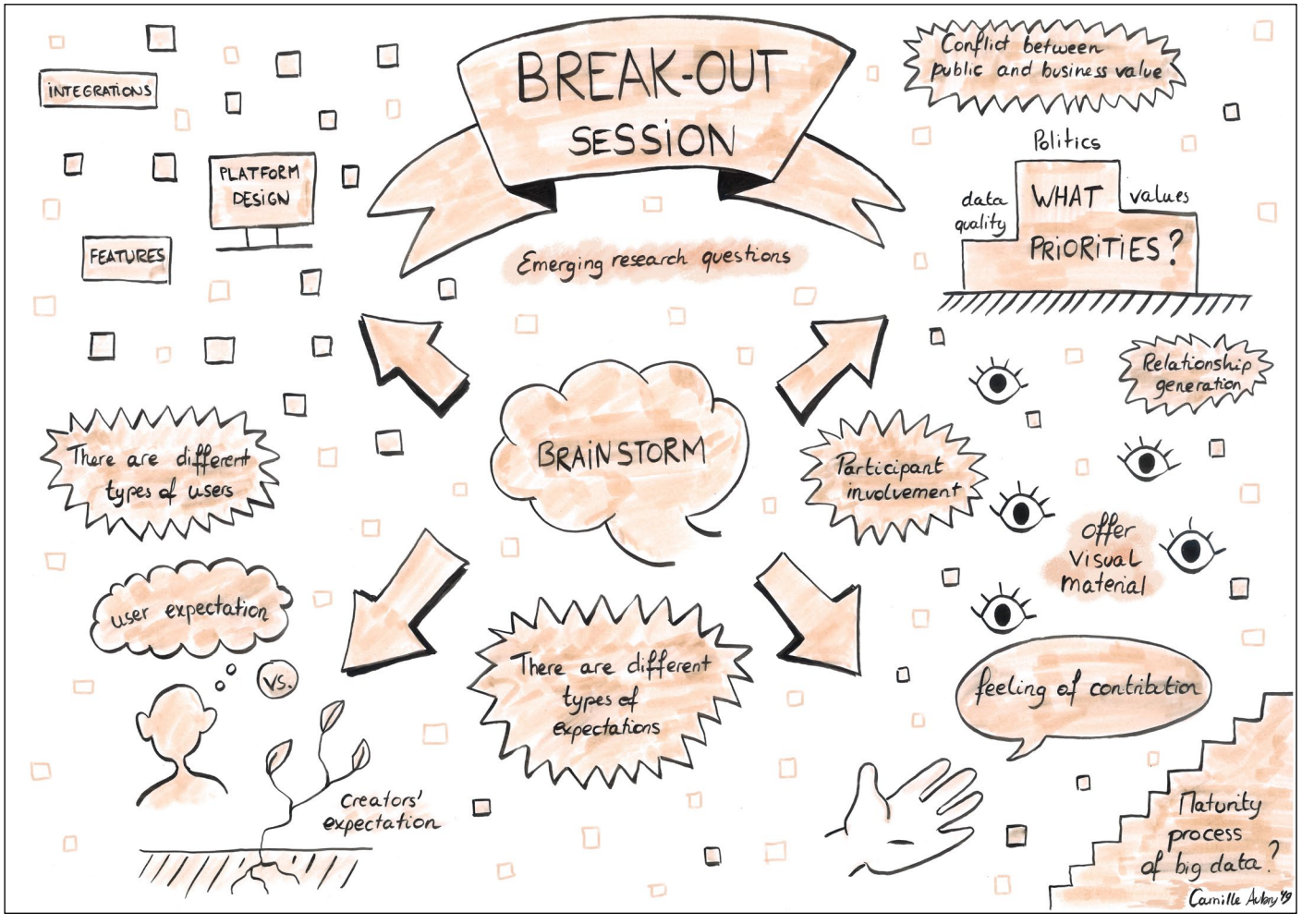

Evidence and Conversations
Some thoughts on evidential pluralism epistemic conflict and health platforms
Sodium Chlorite trials
How is misinformation so easily spread?
Dr. Niccolò Tempini
SODIUM
CHLORITE
WEB-BASED
SPREAD
OF
MYTH
CONSPIRACY
THEORY
ALTERNATIVE
EVIDENCE
USES
HOME BREWED REMEDY
CURE FOR EVERYTHING ?
BUILD
A
COMMUNITY
AROUND
EXPERTISE
"If it cleans the water it could clean your inside!"
where do we draw the line ?
Camille Aubry '19


Dr. Chris Tan
MEDICINE AFRICA
and the value of
online education
SUPPORT
SUSTAINABLE LEARNING
FOUNDED IN 2008
SOMALILAND
Build capacity
Develop professional skills
Support independence
INTRODUCTION OF MENTAL HEALTH
(audio) and text teaching
midwifery
nursing
undergraduate medicine
postgraduate medicine
USE TECHNOLOGY TO SOLVE PROBLEMS
Camille Aubry '19


COMMUNICATION STYLE
All of the content is delivered in English
Engage in back and forth discussions
VALUE IS IN SMALL GROUPS AND LONGITUDINAL WORK
culture has been a learning curve
LOCAL RELEVANCE
CONNECTIVITY
is
A
CHALLENGE
MOODLE
Platform
Hardware quality varies
PASSWORDS
Programme administration
BESPOKE CONTENT
Camille Aubry '19


Constructing health knowledge on Twitter
is it stories or is it science ?
I am interested in how people share their stories of healthcare on social media.
Dr. Stefania Vicari
people
gather
around
hashtags
experiential information vs. medical sources
share information
storytelling
mediated experiences
is it only storytelling ? or science
#my experience
PATIENT ADVOCATES ARE THE MAIN USERS OF MEDICAL QUOTES
But where are the doctors?
Camille Aubry '19


Our journey with Medicine Africa
Transforming commitment into social value in online health communities
Why MedicineAfrica?
growing membership
How do you define VALUE?
Prof. Niki Panteli
This was enabled by digital activism
Dr. Petros Chamakiotis
PHILANTHROPY
MORALITY
RECIPROCITY
developed with and for practitionners
TRANSFERRED KNOWLEDGE
want to develop their skills
opportunity to give back
making better use of free time
CREATE A COMMUNITY
Camille Aubay '19


INTEGRATIONS
PLATFORM DESIGN
FEATURES
BREAK-OUT SESSION
Emerging research questions
Conflict between public and business value
Politics
data quality
WHAT PRIORITIES?
values
Relationship generation
Participant involvement
offer visual material
feeling of contribution
BRAINSTORM
There are different types of users
user expectation
VS.
creators' expectation
There are different types of expectations
Maturity process of big data?
Camille Aubay '19

Directions for Future Research

The workshop ended with a break-out session, depicted on p.8, whereby speakers and audience collectively identified the following questions that future research on health platforms should be addressing:

- Is the potential for social value creation embedded in platforms' design or is it generated independently of it?
- What are the politics of platforms and the politics of values? Whose and what values are promoted on healthcare platforms?
- The ambiguous quality of big health data and their implications for healthcare providers' accountability.
- The ethics of re-using public health data (such as those found on social media and other health platforms) and the ways of doing so for research purposes.

Acknowledgements

This work was supported by a symposium support grant from the Foundation for the Sociology of Health and Illness. We would also like to thank our invited speakers and attendees who contributed to a fruitful and fun workshop, the University of Sussex Business School for hosting the workshop, Corinna Hattersley-Mitchell for supporting it administratively, and Camille Aubry who live-scribed the workshop.

Contact Details

Dr Dimitra Petrakaki
Reader in Information Systems
@DPetrakaki
d.petrakaki@sussex.ac.uk
University of Sussex Business School
University of Sussex
Brighton
BN1 9SL
UK

Dr Petros Chamakiotis
Lecturer in Information Systems
@petros_cham
p.chamakiotis@sussex.ac.uk
University of Sussex Business School
University of Sussex
Brighton
BN1 9SL
UK

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