

Participatory Inclusive Design in Health and Wellbeing

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'Bull Hill'
Anna Dillon

.....from ecology

Geography, BSc Thesis

Ecological survey of
community significant
plants under threat
from damn
construction with the
Yshyr Ebytoso of
lower Pantanal
wetland

Environmental Science, MRes Thesis

Analysis of
sustainability
concepts in local flood
plain management in
the Thames Basin

Climate Change Communication of Science

Centre for Ecology and
Hydrology
Natural History Museum
Websites
Program evaluation

...to health design

**Digital
Media, MSc**

Thesis

Comparison of
frameworks for
engaging with
'users' in
interaction
design

**Interaction/User
Experience
Designer**

AT&T
EzGov
VerticalOne
IBM Interactive
Revolution

**Industrial
Engineering,
PhD**

Thesis

Adoption and
adaption behaviors in
surgical suites with
the introduction of
electronic blood
issuing

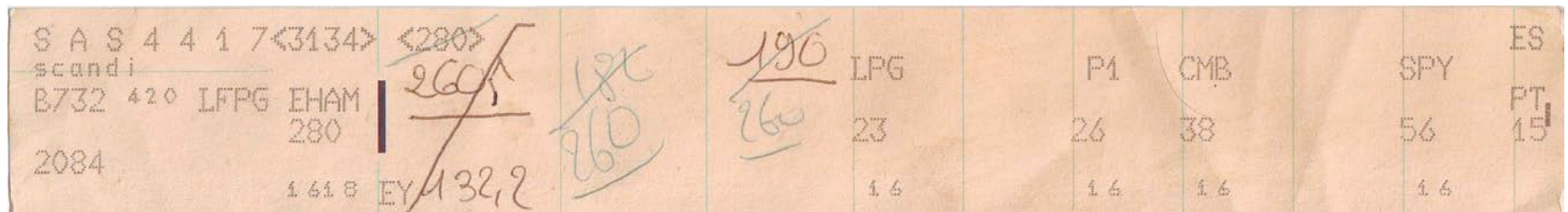
**Assistant
Professor,
OCAD U**

Human factors in
strategic foresight
Inclusive Design
Design for health
Digital Futures

Knowledge Media
Design Institute
University of Toronto

..... questions about humans

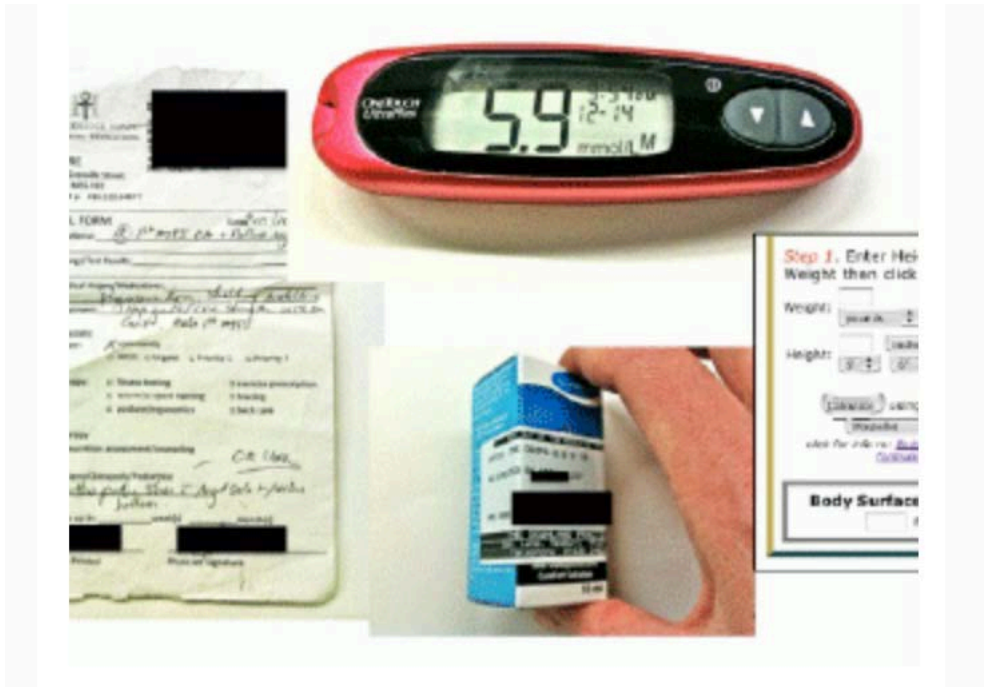
“Why, in this day and age, are planes being handled like breakfast orders in a roadside diner?”



Gladwell, Malcolm (2002-03-25), "The Social Life of Paper", The New Yorker,
http://www.newyorker.com/archive/2002/03/25/020325crbo_books

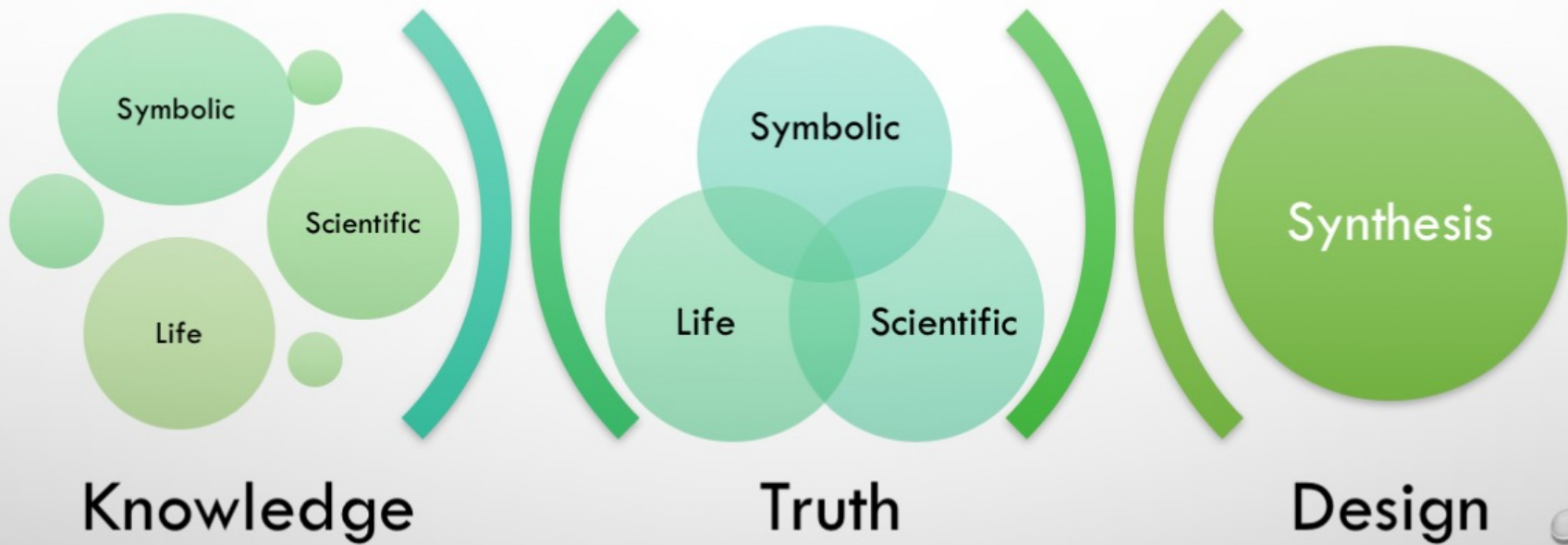
.....design for real experience

Systemic factors make change hard even if everyone agrees things are not optimal

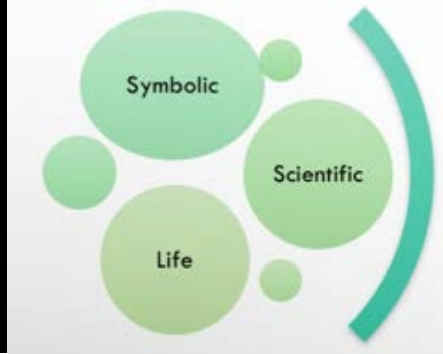


K Sellen, 2016

...the role of design



Truth Regimes



Life

“The mundane everyday experience of health.”

Anyone
Self-evident
Truth vs Lie

Symbolic

“What our leaders tell us about health.”

Only specific figures
Legitimate story
Ritual

Governmental

“Eligibility of the patient – category, behavior.”

Administrator or Holder of policy
Policy and Procedure

Scientific

“The science of health – concepts, experiments, and data.”

Scientists
The evidence
Procedure

Scientific truths about health



Cochrane

Trusted evidence.
Informed decisions.
Better health.



Governmental truth about health

Service categories – i.e. long term care vs. high need care

Recommended referral rates for tests and specialty consults

Reporting and testing requirements

Eligibility criteria

Forms

Policy documents

Public health campaigns

Symbolic truth about health

A black and white image of a handwritten signature in cursive script, which reads "Oprah Winfrey".

By Connormah, Oprah Winfrey [Public domain or Public domain],
via Wikimedia Commons

NatureWorksBest[®]
CANCER CLINIC
Baking Soda Cancer Treatment



The Gazette Review, 2015 accessed at
<https://gazettereview.com/2015/04/dr-oz-addressing-criticism-on-upcoming-show/>

Symbolic truth of the physician



By Seattle Municipal Archives from Seattle, WA (Doctors with patient, 1999) [CC BY 2.0 (<http://creativecommons.org/licenses/by/2.0>)], via Wikimedia Commons

Everyday truth through experience



"I found a treatment that worked well for others, and decided to go for it. I haven't had a seizure since! Now my experience is helping new patients



Diabetes Self-Mgmt
@ManageDiabetes



#diabetestips Should I alter my medicine regimen on stressful days? bit.ly/TyBET

RETWEETS
2

FAVORITES
4



6:33 AM - 10 Jul 2015



patientslikeme®

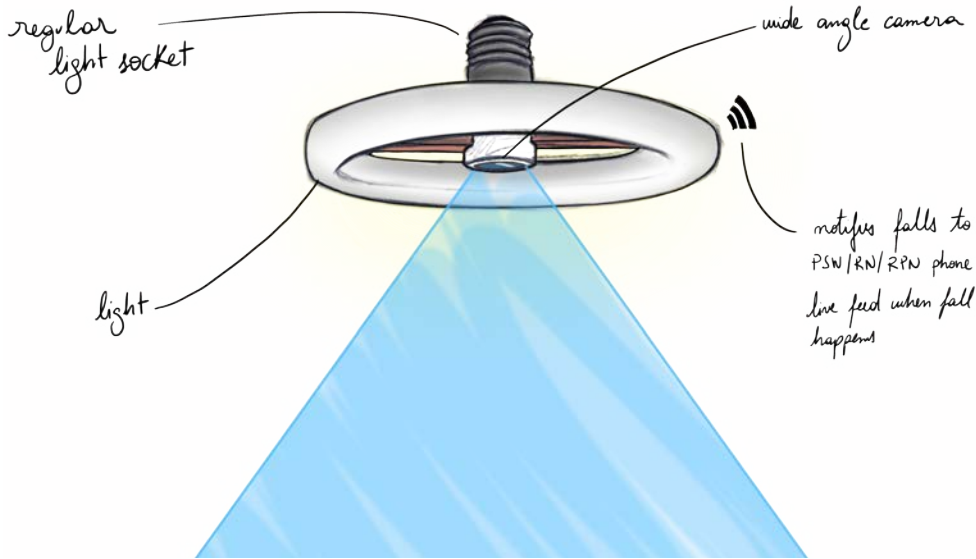
http://www.healthline.com/hlcmsresource/images/topic_centers/Diabetes/best-twitter/best-diabetes-twitter.png

Truth Game Tool - falls

	Mundane	Symbolic	Governmental	Scientific
Story Summary	Nurses say the alarms don't work	Our falls program is world class	Patients should not be sedated unless criteria are met	Falls are diverse with different outcomes
Who speaks the truth?	Nurse, Patient, family member	Practice leaders	Administrator	Falls researchers
Truth vs. Non-Truth	my experience vs. yours	"our program" vs everything else	definition of criteria vs. other factors impacting care	data on falls and science of 'long lie'
Truth Arises from..	Experience	Thought leaders	Ministry review	Studying falls
Truth is represented as..	Anecdote/story	Through story and ritual	Policy	Evidence base

Design for Health student, Filipe Ligabue and Alison Mulvale working with Baycrest to address falls in longterm care.

Faculty: R Hunt, J Goss



“Reframe fall prevention and act on minimizing the consequences of falls”



<http://iatsl.org/projects/ers.htm>



SOONER – overdose first aid

- Co-design
- Pan-Canadian Working Group
- Community Engagement
- Ultra-brief training
- Kit (pouch) to give out
- Emergency Room, Addictions, Family Medicine



.....integrating

Health Studio work on first aid for overdose with community partners, and St Michael's Hospital.

EDITORIAL

THE AMERICAN JOURNAL OF MEDICINE



Stop Talking 'Dirty': Clinicians, Language, and Quality of Care for the Leading Cause of Preventable Death in the United States

A patient with diabetes has "an elevated glucose" level. A patient with cardiovascular disease has "a positive exercise tolerance test" result. A clinician *within* the health care setting addresses the results. An "addict" is not "clean"—he has been "abusing" drugs and has a "dirty" urine sample. Someone *outside* the system that cares for all other health conditions addresses the results. In the worst case, the drug use is addressed by incarceration.

On December 9, 2013, the first ever reform summit was held at the... of this summit...

despite harmful consequences. Yet, despite evidence of a strong causal role for genetics and impairment in inhibitory control, stigma is alive and well. Research is now revealing that one contributory factor to the perpetuation of stigma may be the type of language we use.

Use of the more medically and scientifically accurate "substance use disorder" terminology is linked to a public health approach that captures the medical malfunction inherent in addiction. Use of this term may decrease stigma and increase help-seeking. In contrast, tough, punitive, and language, including the word "war," in "war on drugs," is intended to send an uncompromising message, "You use, you lose," in the hopes of deterring drug involvement. Accompanying this aggressive rhetoric are terms such as drug "abuse" and drug "abusers," implying willful misconduct (ie, "they can help it and it is their fault"). This language increases stigma and reduces help-seeking. Since the 1970s, such language has become the norm. In our federal health institutions that address addictions, the term "abuse" in their names (eg, Institute for Drug Abuse), and their materials often refer to individuals as substance "abusers."

we call it? Rhetorical or... ing the use of stigmatizing... science on the issue to info... ted at the White House S... (1) was randomly... -level mental health... ng an individual in... s. In half the vignette... substance abuser,"... as "having a... rios were id... abuser" te... person as d... individual... The sa... e, an... me...

informa healthcare

Substance Use & Misuse, 48:558-567, 2013
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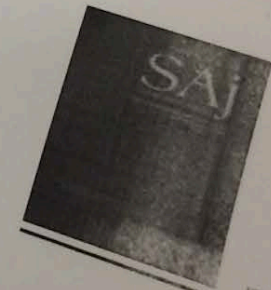
ORIGINAL ARTICLE

Barriers to Medical Provider Support for Prescription Naloxone As Overdose Antidote for Lay Responders

Traci C. Green^{1,2}, Sarah E. Bowman², Nickolas D. Zaller^{1,3}, Madeline Ray², Patricia Case⁴ and Robert Heimer⁵

¹The Warren Alpert Medical School of Brown University, Providence, Rhode Island, USA; ²Emergency Medicine, Rhode Island Hospital, Providence, Rhode Island, USA; ³Division of Infectious Diseases, The Miriam Hospital, Providence, Rhode Island, USA; ⁴Fenway Community Health, Boston, Massachusetts, USA; ⁵Yale School of Public Health, New Haven, Connecticut, USA

The use of take-home prescribed naloxone by laypersons... approach recently endorsed by the American Medical Association (AMA) and response trainings... in conjunction...



Substance Use & Misuse

ISSN: 0889-7077 (Print)

Assessment #naloxone

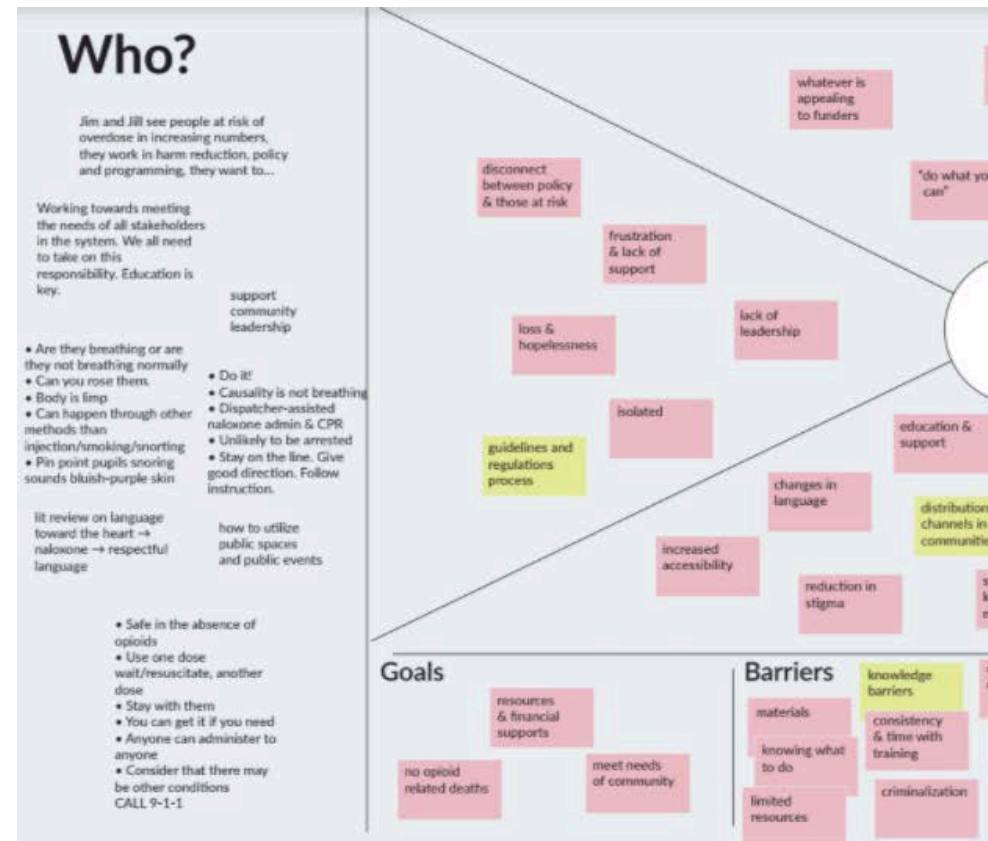
..... community

Health Design Studios at OCADU are situated on the ancestral and traditional territories of the Mississauga of the New Credit, the Haudenosaunee, the Anishinaabe and the Huron-Wendat



..... participation, inclusion, co-design

- Community committee - 8
- Co-investigators - 2
- Site representatives - 3
- Program representatives – 2
- Multi-stakeholder workshop
- Iterative Co-design Sessions across and at each setting



..... participation, inclusion, co-design

- Multi-stakeholder workshop - 27
- First responders
- People who use drugs
- Family/friends
- Program managers
- Frontline clinical

	WHAT ABOUT AWARENESS & INFORMATION?	WHAT ABOUT RESOURCES?
ACTIONS	<ul style="list-style-type: none"> develop & manage a data surveillance system communication plan/ media plan education plan/usability & clumsiness identify gaps and goals of community identify measures of success create a data collection template culturally specific awareness & info evaluate existing tools and resources emphasis on prevention collaborate with organizations prevent reinvents the wheel 	<ul style="list-style-type: none"> ethics collaborate with organizations prevent reinvents the wheel *stand → inv or
TOUCHPOINTS	<ul style="list-style-type: none"> primary care/ addiction clinics government media social media community partner politicians & votes constituents focus groups -community -public spaces - support groups first aid organization information systems user acceptability testing mit correction services ED/EMS partnership with police/ law enforcement 	<ul style="list-style-type: none"> bars & music festivals home shelters
QUESTIONS	<ul style="list-style-type: none"> ethics privacy how to get government leadership? will the media deliver the correct message? how to get input from the stakeholders? how do we learn from other provinces? 	<ul style="list-style-type: none"> what other partners are out there? legal implications
FEELINGS/ THOUGHTS	<ul style="list-style-type: none"> overwhelmed 	

..... participation, inclusion, co-design

- Language and comprehension
- Live action vs. animation
- Iconography of first aid
- Language of first aid vs. drug use
- Discretion vs. discoverable
- Durable vs. disposable
- Context and implementation
 - Family medicine
 - Addictions
 - Emergency department

Design as integration thank you

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