DESIGN BY EXCEPTION

**OUTLIERS, MISFITS AND THE DESIGN OF
EXTRAORDINARY HEALTHCARE**

TAI M. HUYNH

DESIGN BY EXCEPTION:

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EXTRAORDINARY HEALTHCARE

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ABSTRACT

Medicare was created to serve all Canadians. This fact also makes the design of healthcare products and services challenging because the user base is hugely diverse. In our quest for universality, it might be appealing to target our designs at mainstream users first, and then make adjustments to accommodate the needs of users who we might consider to be "outliers". But there's a different approach, one that does the complete opposite, that promises to be more effective at coming up with breakthrough products and services. This approach targets not the majority but the fringe users first, under the theory that users with exceptional needs provide the best ideas, and that products and services developed to meet these needs could, in time, also appeal to mainstream users. Through a careful review of the literature and the application of these concepts to the student's own work, this paper explores the roles of outliers in the design of healthcare products and services. It makes the distinction between those with design agency (ability to design their own solutions) and those without, and proposes a framework, *design by exception,* in which outliers are sought after, rather than accommodated, in healthcare design projects.

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Image 02: *City Scene.* Grigory Kruglov. January 26, 2011.

On this chilly February morning, Dr. Jeffrey Turnbull and his team are gathered in the basement of an old two-story brick building in Ottawa's Lower Town district to prepare for another hectic day of patient visits. But these aren't the typical visits where sick patients go see their doctors. No, on these visits Turnbull is the one doing the visiting. And these aren't your typical patients either. They're Ottawa's homeless.

Without a home, living on the street or going from shelter to shelter, these individuals are exposed to extreme cold, infectious diseases and violence, and often have multiple mental and physical health problems, as well as addiction to drugs and alcohol. And the mainstream healthcare system is not set up to address their needs in any meaningful way.

With morning rounds completed, and cars loaded with supplies and patient charts, Turnbull and his crew roll out of the snowy parking lot and head towards The Shepherds of Good Hope, the first of five homeless shelters they'll be visiting this day.

Turnbull is not the kind of doctor you'd expect to find at the helm of such a modest operation. After all, he's the top doctor (Chief of Staff) at The Ottawa Hospital, one of Canada's largest and most respected teaching hospitals. He's also the former president of the Canadian Medical Association, a 150-year old establishment representing the country's 80,000 physicians. So why is he out here?

Every Friday and Saturday night, his hospital's emergency department is overrun with homeless patients. They're brought in by ambulance, and often by police. And many are familiar faces. In fact, one patient was in the emerg 191 times before the program started. Turnbull recognized that what his hospital was providing was not good care, and it was very expensive for the healthcare system. In short, the mainstream healthcare establishment was failing this segment of the population.

"Traditionally we have an approach where we say 'one size fits all'; you come here and you get your care and if you don't get your care, that's not our problem." Turnbull reflects. "This moves the care to a patient-centre or client-centred approach. It takes a unique population and says 'how can we bring care to you, on your terms?'"

In the lounge area at The Shepherds of Good Hope, Turnbull and his interdisciplinary team slowly make their way from one corner of the room to another, stopping to see patients as they go. They all greet him with a friendly "Hello, Dr. T!" – a sign of the street cred he's earned over the years doing this kind of work.

For more on this case study, visit: uhnopenlab.ca/project/pop-health

INTRO DUCTION

Unfortunately, the kind of innovative, outside-the-box thinking embodied in Turnbull's approach stands out as the exception rather than the rule in contemporary healthcare. The failure to address needs that are beyond what would normally be considered mainstream is quite pervasive in healthcare, and occurs at many levels. Here are just a few examples:

SYSTEM LEVEL

- People who don't have a healthy place to live – those who are homeless or inadequately housed – face major problems accessing the healthcare they need, and have poorer physical and mental health[1]

- People with low socio-economic status are hospitalized more frequently,[2] and a significant percentage cannot fill the prescriptions they were prescribed because they cannot afford them[3]

FACILITY LEVEL

- Morbidly obese patients are injured at a rate 12 times higher than the general patient population due to the lack of equipment that is big and strong enough to support their weight[4]

- Older seniors are challenged by the fast-paced, overcrowded and chaotic environment of the emergency department, which tends to also lack orientation and wayfinding cues as well as seniors-friendly equipment and furniture[5]

HUMAN LEVEL

- Older adults with reduced visual acuity face increased sensitivity to glare and risk of falls, and yet most healthcare facilities are covered in glossy floors that are frequently waxed and polished to a shine[6]

- Patients with literacy problems are unable to follow prescription directions that might appear simple to trained clinicians; for example, the ubiquitous instruction "Take 1 tablet X times a day" results in medication being taken at inappropriate times or intervals, or in the wrong quantities, whereas "Take 1 tablet every X hours" would be much easier for everyone to follow[7]

These problems are particularly troubling since those most in need are often the ones hit hardest by these shortcomings in service and product design. But how can this be, when Medicare is supposed to be universal?

Here's how *universality* is defined under the Canada Health Act:

> *"In order to satisfy the criterion respecting universality, the health care insurance plan of a province must entitle one hundred per cent of the insured persons of the province to the insured health services provided for by the plan on uniform terms and conditions."[8]*

The language of "uniform terms and conditions" was probably drafted by lawmakers to ensure that health plans do not discriminate against anyone. Unfortunately, and despite being well-meaning, this has manifested the healthcare frontlines in ways that often fall short of its spirit. What Dr. Turnbull refers to as "one size fits all" exemplifies this manifestation. So is the frequently used response to patient demands: "Sorry ma'am, I'd love to do that for you, but I can't because then I'd have to do it everybody else." Surely, "uniform" cannot equal "design by the lowest common denominator". It must not.

Canadians have long considered universal healthcare among their most cherished of institutions, as an embodiment of their values and an icon of the national identity. However, there are signals indicating that their confidence is eroding; recent public opinion polls indicate that the majority of Canadians believe that healthcare is in a "state of crisis" and needs "complete rebuilding" or "fairly major repairs".[9] There is clearly an appetite for shaking things up, for new ways of thinking and doing.

This paper explores one of these potential new ways. In contrast to the tendency to design for the "average" person, it examines how doing the complete opposite can lead to extraordinary results. It goes beyond the "health equity" imperative of looking after the needs of marginalized groups by asking not what the system can do for them, but what they can do for the system. More specifically, it

explores how designing for and with exceptional users can lead to breakthrough innovations that have the potential to benefit all of us.

STRUCTURE OF THIS PAPER

This paper is organized into the following chapters:

The Average User Fallacy · The "average" user is just a statistic. This chapter draws on decades old research to show that the "average" user is a fictitious concept that can deceive us into designing compromised products and services that meet the needs of very few people.

Design Philosophies · If the spectrum of possible users is broad and diverse, then for whom should we design? This chapter examines various schools of thought on this question, and discusses the roles played by "extreme users", "lead users" and "users with special needs" – collectively referred to in this paper as "exceptional users".

Design Agency · This chapter makes the distinction between exceptional users who possess design capabilities and those who do not, and the different approaches for working with them. The chapter includes a case study involving a group of older seniors' frustration with the existing health system and their attempt to design their own.

Design Gallery · Many of the products and services that are commonplace around us were originally designed for/by users with exceptional needs. This chapter is a gallery of inspiring examples.

Mainstreaming · To the extent that achieving mainstream adoption of a niche product or service is desirable, this chapter discusses factors important to that process.

The PODS Case Study and Critical Reflection · This chapter presents an in-depth case study of, and critical reflection on, the author's project to design a patient-oriented discharge summary (PODS), which attempted to apply many of the concepts described in this paper.

Conclusion · This paper concludes with a summary of the main concepts discussed, including their limitations, as well as ideas for future development.

METHODS

This MRP takes the form of reflections and insights gained from the author's own practice related to the design of healthcare for exceptional users. The MRP uses a narrative approach to explore case studies from this practice, supported by auto-ethnographic interpretation. These experiences are complemented by insights from a literature review. Each technique is further detailed below:

1 Literature Review · A literature review was conducted to identify approaches used in designing for "exceptional users". The literature review included peer-reviewed and trade literature, as well as books, films and doctoral dissertations. Search of the peer-reviewed literature was conducted through Google Scholar and Scholar's Portal. Other literatures were identified through the Google search engine. Both types of searches employed a variety of terms relevant to the domains of inquiry, with the main ones being "extreme users", "lead users" and "users with special needs".

2 Case Studies · The author's own work is presented as *narrative case studies*,[10,11] which, as the name implies, is a blend of narrative and case study forms. This particular variant of the case study method was chosen because its storytelling orientation is well suited for illustrating the challenges, actions and nuanced happenings of users as human beings as they interact with their medical and social worlds. For the main case study – the design of the patient-oriented discharge summary (PODS) – auto-ethnographic interpretation is used, based on the critical reflection method, consisting of descriptive, reflective, and critical phases.[12,13,14,15]

No specific research ethics board approval was sought for this MRP as it did not involve any direct participants or primary research. All prior works referenced here were subject to research ethics board review and consideration during original project undertaking.

THE AVERAGE USER FALLACY

The "one size fits all" approach referred to by Dr. Turnbull is something quite pervasive in healthcare. One of the greatest challenges faced by Canada's publicly funded healthcare system is how to design products and services for a user base that includes virtually everyone. As designers on a quest to develop things that appeal to the widest possible audience, there is a tendency to focus our design efforts on the "average" user – whose needs are thought to be common.

Since the early 1950s, we've known that designing for the "average person" is a fallacy.[16] But let's imagine for a moment that we're in the 1940s and didn't know this. And let's say somebody asked us to design a flight suit for fighter pilots. We might start by taking body measurements of pilots – height, chest circumference, sleeve length, etc. We might crunch the data, get a series of average dimensions, and build a scaled mannequin to work from. We might even give him a name, say "Pilot Bob", and then spend the next 6 months prototyping a suit for Bob.

This approach seems logical, but it's dead wrong. Because chances are, the flight suit that we design for Pilot Bob will fit not a single pilot out there in the real world.

In 1952, aerospace researcher Gilbert Daniels published a brilliantly simple study demonstrating that the "average man" is so rare as to be non-existent in real life.[17] He examined the body dimensions of over 4000 pilots to see how many of them could be considered "approximately average" (within plus and minus 15 percent of the mean) across 10 dimensions useful in clothing design. The results were pretty striking; while 1 in 4 pilots were average on one dimension, only 7 in 100 could be considered average on two dimensions, and by the time he considered four dimensions, the "average man" became vanishingly rare.

It is of course discouraging to know that even when we design for what we think is the fat part of the distribution curve - the middle 30 percent - we'll get it wrong. And yet, when you think about it, it does make sense; people are so diverse that a person can be average on one dimension, yet an outlier on another.

The truth is, many of us in healthcare still tackle design problems using this "average man" approach today. But no one starts a design project saying they're going to intentionally make it difficult for marginal users. It's more often than not an unintended consequence of trying to design for everybody. It's probably more accurate to say that most designers set their sights on the "average" user first. And then if we need to, we can later on make adjustments to our designs to accommodate the needs of users who we might consider to be "outliers". But in reality, we sometimes never truly get to that second stage.

	Percent of original
(1) Of the original 4063 men, 1055 were of approximately average stature.	25.9
(2) Of these 1055 men, 302 were also of approximately average chest circumference.	7.4
(3) Of these 302 men, 143 were also of approxmately average sleeve length.	3.5
(4) Of these 143 men, 73 were also of approximately average crotch height.	1.8
(5) Of these 73 men, 28 were also of approximately average torso circumference.	0.69

Figure 01:
Average Body Dimensions of Pilots.
Hertzberg, H.T.E., 1960.[18]

DESIGN PHILO SOPHIES

Why do designers put the needs of some over the needs of others? This chapter describes the different design philosophies behind such choices.

There are different schools of thought for dealing with the spectrum of possible users of a product or service. These fall into one of three categories: "mainstream design", "design for all" and "design by exception". In the figure below, we see that the three approaches emphasize different parts of the user spectrum.
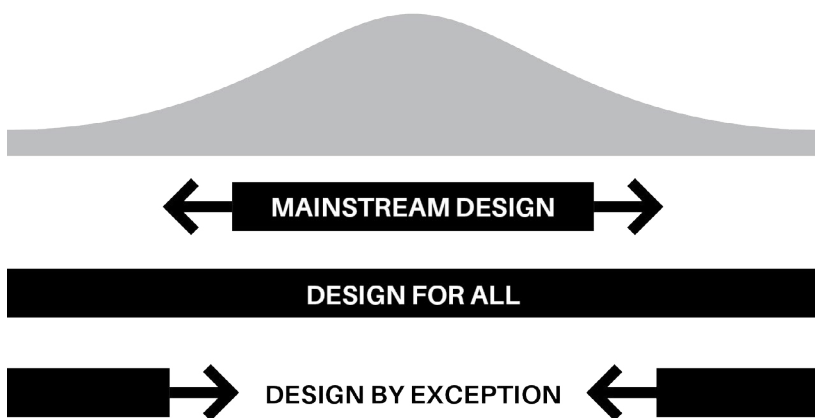

Figure 02:
Design Philosophies

MAINSTREAM DESIGN

This is the traditional, commercially driven approach. Designers using this approach target their products and services at the fat part of the distribution curve - the largest segment of customers. Designers might conduct user research on people representative of this group and they might develop personas based on this research to get a precise description of user needs. The aim is to hone in on one particular person or archetype. Alan Cooper, one of the biggest proponents of the use of personas in the design process suggests that "The broader a target you aim for, the more certainty you have of missing the bull's-eye." [19]

And so fringe users are usually considered after the fact, as a sort of second-class citizen in the universe of users. Attempts might be made to accommodate their unusual demands, but this tends to happen towards the end of the design cycle. This can lead to design features that might be considered as "add-ons" to an otherwise well designed or elegantly simple solution. Or worse, the piling on of special requirements risks diluting the usefulness and usability for everyone if inappropriate compromises are made to accommodate fringe users.[20]

Another important consideration is that while mainstream users can help us design products and services that are incrementally better than what currently exist, they are constrained in their ability to offer ideas and insights for breakthrough designs.[21]
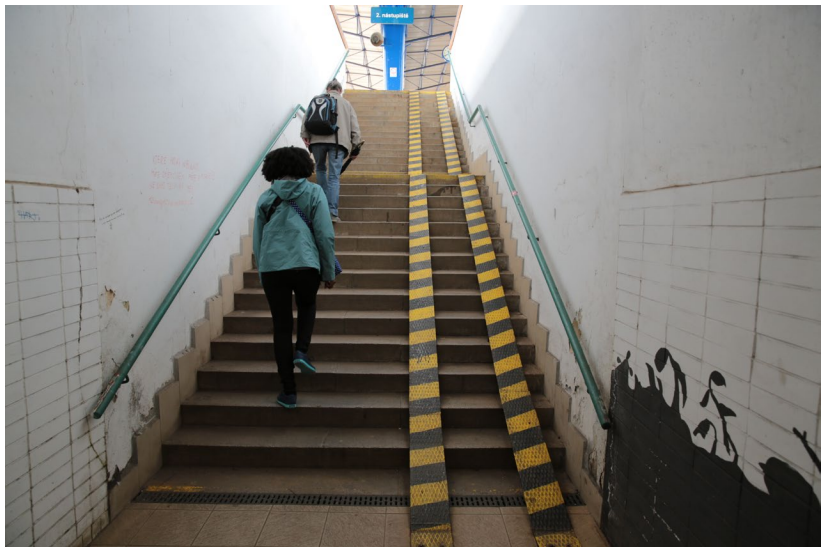

Image 03:
Wheelchair Ramp.
Chris Waits, May 14, 2014.

Conventional user research tends to ask typical users – or even worse, non-users – what they think they need. The problem with this approach is that average users cannot say with any degree of certainty what they might need in the future and so they speculate or ask for improvements that are general and obvious, like making things "cheaper" or "faster" or "easier" to use. [22]

"If I had asked people what they wanted,
they would have said faster horses."

-Henry Ford

DESIGN FOR ALL

Universal design refers to "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design."[23]

While its intended scope has always been broader, the practice of *universal design* has historically focused on the built environment or physical products, with particular emphasis on ensuring that they work for disabled and non-disabled people alike.[24]

Acknowledging that while the goals of *universal design* are noble, critics of the approach argue that it is virtually impossible to achieve; that a designer ends up with a user group with wide-ranging characteristics and abilities – much wider than traditional user-centred design is capable of addressing.[25]

The related concept of *inclusive design* refers to "design that considers the full range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference."[26]

In this way, *inclusive design* is very similar to *universal design*. In fact, OCAD University's Inclusive Design Research Centre indicates that "Inclusive Design, as we use it, can be seen as Universal Design with a number of provisos. When we chose the term we wanted to distinguish it from the then current associations with the term Universal Design. The associations that we want to avoid are not

necessarily part of any formalized definition of Universal Design, but nevertheless are part of the popular assumptions about the term."[27] These popular assumptions have to do with the perception that *universal design* is about architecture and industrial design, which is really where it all began. This perception is closely linked to another perception that proponents of *inclusive design* want to shake, and that's *universal design's* strong association with disabilities and its historical roots in the disability rights movement of the 1960s. Although they share the same goal of creating products and services that are usable by all, the emergence of the digital medium over the past decade has become the source of differentiation for *inclusive design*. This is because one-size-fits-all solutions - the hallmark of good *universal design* - are no longer needed due to the potential of the digital medium to create infinitely personalizable solutions that work for everyone.

DESIGN BY EXCEPTION

Design by exception is a term introduced in this paper to help draw connections among three distinct but related concepts that share a common emphasis on designing for people with fringe needs: *design for special needs*, *extreme users design* and *lead user innovation*. Related to these concepts is the theory that products and services designed to meet their unusual needs might lead to breakthrough solutions, and that in time, these solutions might also appeal to mainstream users.

Design for Special Needs

Design for special needs focuses on developing solutions for people with disabilities, such as those requiring hearing aids, prosthetic limbs or communication aids. Design for special needs as a field exists mostly to counteract the shortcomings of mainstream design, which often leave the needs of disabled people out of the design equation.

Not surprisingly, within certain design circles, *design for special needs* has become a marginalized concept, ostensibly replaced by the *universal* or *inclusive design* ethos. This is because the very notion that some people need to be accommodated through specialized design connotes the existence of a sort of dual-class system of 'general' versus 'special' needs, with the latter somehow being a secondary concern.[28,29]

Extreme User Design

> *"When you speak with and observe extreme users,*
> *their needs are amplified and their work-arounds*
> *are often more notable."*
>
> - Stanford D.School

The biggest proponents of the *extreme user design* approach are the Hasso Plattner Institute of Design at Stanford (D.School)[30] and the design firm IDEO.[31] The approach involves identifying *extreme users*, interviewing them and/or observing their behaviour with a product or an activity important to the design challenge at hand.

The D.School describes the following process for identifying extreme users:

> "Determining who is an extreme user starts with considering what aspect of your design challenge you want to explore to an extreme. List a number of facets to explore within your design space. Then think of people who may be extreme in those facets. For example, if you are redesigning the grocery store shopping experience you might consider the following aspects: how groceries are gathered, how payment is made, how purchase choices are made, how people get their groceries home, etc. Then to consider the aspect of gathering groceries, for example, you might talk to professional shoppers, someone who uses a shopping cart to gather recyclables (and thus overloads the cart), product pullers for online buyers, people who bring their kids shopping with them, or someone who doesn't go to grocery stores."[32]

Lead User Innovation

Lead users "face needs that will be general in a marketplace – but face them months or years before the bulk of that marketplace encounters them, and are positioned to benefit significantly by obtaining a solution to those needs."[33] *Lead users* are therefore considered *user-innovators* because they seek to develop solutions that do not already exist in the marketplace in order to address their unique needs.

Lead users have been found to be the source of numerous breakthrough products across many industries.[34] For example, one study found that close to 60 percent of new pharmacotherapies originate from practicing clinicians, often through off-label use of existing drugs.[35]

Extreme and *lead users* who are dissatisfied and highly experienced in the challenges associated with their unmet needs often provide the best ideas.[36]

Strengths and Weaknesses

Clearly, there are pros and cons associated with each of the three approaches discussed above: *mainstream design, design for all and design by exception.*

Mainstream design is weak in its ability to come up with equitable products and services, but is attractive because it is an easier path for designers to follow, the users are more identifiable and their needs are more relatable. Conversely, *design for all* has the potential to create equitable products and services, but is more challenging for designers at the practical level. Because of the need to appeal to a wide audience, there is always the risk of making compromises that lead to uninspiring and un-innovative designs. Finally, *design by exception* hits the middle ground in terms of equity, but excels in its potential for coming up with breakthrough rather than incremental products and services. This feature is particularly appealing given the chronic lack of innovation in the healthcare space.
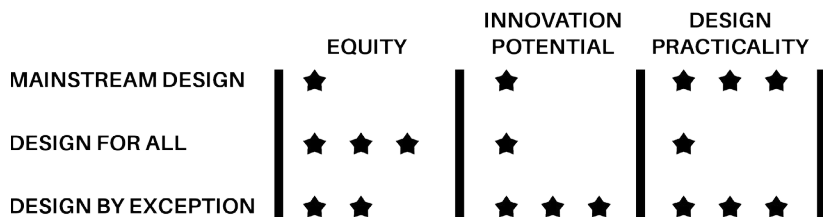
	EQUITY	INNOVATION POTENTIAL	DESIGN PRACTICALITY
MAINSTREAM DESIGN	★	★	★ ★ ★
DESIGN FOR ALL	★ ★ ★	★	★
DESIGN BY EXCEPTION	★ ★	★ ★ ★	★ ★ ★

Figure 03:
*Design Philosophies,
Strengths and Weaknesses*

HIGH
"DESIGN AGENCY"

LEAD USER
INNOVATION

DESIGN FOR
SPECIAL NEEDS

EXTREME USER
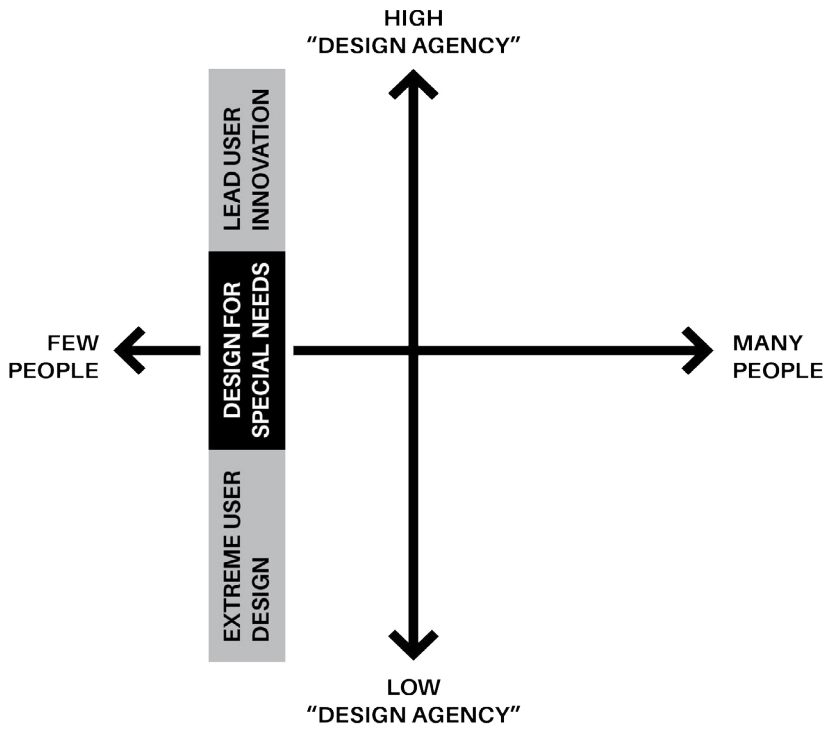DESIGN

FEW
PEOPLE

MANY
PEOPLE

LOW
"DESIGN AGENCY"

Figure 04:
Design Agency

17

DESIGN AGENCY

While *design for special needs*, *extreme user design* and *lead user innovation* share the common goal of creating solutions for outliers, they differ markedly in mannerism and attitude. *Design for special needs* is often associated with disability and accommodation, while designing for *extreme* and *lead users* is often associated with user empowerment and ingenuity.

Even more interesting are the differences between the *extreme user* and *lead user* approaches. The way the *extreme user* approach has been framed assumes that while these users might have extreme needs, they are limited in their ability to design solutions to satisfy those needs. Professional designers are the ones that do the designing, while *extreme users* are the source of information and insights on needs and desires. In other words, *extreme users* are assumed to have little *design agency* – the ability to design products and services that satisfy one's own needs and desires.

On the other hand, *lead users* are a special breed possessing both extreme needs and the ability to design solutions for themselves, and for this reason, the term *user-innovator* is often used interchangeably.[37] While designers working with *extreme users* need to use design research techniques to uncover their needs, *lead users* already possess that knowledge. This is important because not all user knowledge can be transferred effectively or without loss in fidelity. This is especially true for *tacit* knowledge, which is a form of "sticky information" that tends to be difficult to transfer from one person to another.[38]

Information that can be coded in explicit terms (e.g. a blueprint for a building) can be easily transferred from one individual or locus to another. However, many

human skills and much of human expertise are of a tacit nature, and are therefore not easily transferable. From this point of view, both users and designers possess tacit knowledge, and problem solving requires the effective and efficient connection of information on user needs with problem-solving capabilities.

In this sense, the ultimate designer is a user who designs. This makes a lot of sense when we think about who's behind the breakthrough innovations we see around us. Steve Jobs and Bill Gates come to mind.

Given the tacit nature of a lot of patient-level information, one could reason that clinicians working at the frontlines of healthcare are well positioned to be innovators. One study suggests that this might indeed be the case. In this study, the authors identified and followed a set of new drug molecules approved by the FDA in 1998 for 5 years and traced their patterns of subsequent new drug applications (new uses) for these molecules. Of the 143 new drug therapy that emerged, 57 percent were discovered by practicing clinicians through a process called off-label use.[39] In other words, users (prescribers, to be more accurate) of drugs were more effective at discovering new uses than the R&D departments of large drug manufacturers.

Traditionally, the healthcare industry has conceived of patients as people with little *design agency* – as passive users of healthcare products and services. This mindset is deeply rooted in the power differential between providers and patients, which is itself rooted in the hierarchy of knowledge, with highly specialized clinical professionals at the top. In the realms of medicine, surgery, pharmaceuticals, and the like, they are indeed the experts. But increasingly, healthcare and generally health, is becoming more than the curing of illness. In this new world, patients too are experts - in how they experience an illness, a set of life circumstances, the care they receive or the health system with which they interact. This kind of knowledge is mainly *tacit*. And as such, they are the Steve Jobs and Bill Gates of this new world– the people best positioned to come up with breakthrough solutions.

In the opening chapter, I told the story of Dr. Jeffrey Turnbull and the quest to redesign the way healthcare is delivered to homeless people in Ottawa's inner city. It illustrated the amazing impact the healthcare system can have when it shifts from a "one-size-fits-all" to a "design for special needs" approach. However, as the next case study illustrates, sometimes it is not providers, but patients who are the architects of change.

SENIORS SELF-DESIGN

Meet 85-year old Christine McMillan. About five years ago, in an apartment building located in the Hillendale district of Kingston, Ontario, Christine and a dozen older seniors began a quiet revolution. Like most other places in society where seniors are 'housed', they lived socially isolated lives.

"Most of the seniors do not have immediate family in the area. They were frightened of dying alone at night, and no one finding them for days," said

McMillan. "If you don't drive and you're stuck in a home or apartment, you're alone all the time and we know that isolation affects health. The second thing was nutrition. They didn't bother getting dressed. They left their nighties and housecoats on. They would sit and watch TV. When they finally decide that they should have something to eat, they'd have tea and toast. And most of them no longer drove. They had lost the friends that used to drive them to church; they'd died. So basically their lives were in the apartment."

The building's corridors were empty, quiet and echoed the social isolation within the units. Many were on wait lists to move into long-term care facilities to live out their remaining days. This way of living was robbing them of their mental and physical health, their sense of social connectedness and agency. Something needed to change. And government programs like home care and long-term care were not addressing the interrelated issues of health, friendship and independence.

Seeing an opportunity to do better, Christine called a meeting and brought forth the idea of having communal meals as a way to combat social isolation. It worked wonderfully. But they didn't stop there. They introduced an exercise program to stay active. They brought in a personal support worker stationed right in the building who would get to know them and be ready to lend a helping hand at a moment's notice. A corps of volunteers from the surrounding community was formed to help with meals and social activities. The building owner gave them the basement space for a common lounge where they could socialize, play and learn.

In a matter of months, the seniors succeeded in creating an entire supported living program for themselves, right in the building. When it began, 15 of the residents were on the wait list to move into long-term care. Because of the services they collectively designed, they all elected to forgo the long-term care option, saving the health care system hundreds of thousands of dollars a year.

Today, 58 of the 60 units are occupied by seniors. And the telephone is ringing off the hook with others who have heard about this innovative building and want to join in.

For more on this case study, visit: oasis.uhnopenlab.ca

CO-DESIGN

Somewhere between Dr. Jeffrey Turnbull and Christine McMillan's approaches – the former is provider-led while the latter is patient-led – lies the concept of "co-design". In healthcare, the term *co-design* refers to patients and providers working in partnership to improve services.[40]

In this way, co-design is synonymous with the concept and practice of "participatory design", which starts with the simple premise that those affected by a design should have a say in the design process.[41] It is interesting to note that participatory design originated in Scandinavian countries during the 1960s and 1970s, rooted in the work of trade unions. At the time, it was known as "cooperative design", and its focus was on improving the environment, tools and processes for workers. An important motivation behind *participatory design* was the observed power imbalance among stakeholders, and so the approach sought to rebalance that relationship through design strategies and methods that allowed resource-weak stakeholders (e.g. workers) to effectively and legitimately participate in the design process traditionally controlled by resource-strong stakeholders (e.g. employers).

In a similar way, but separated by several decades, healthcare is now beginning to acknowledge that the power imbalance between patients and providers is one that needs to be corrected. The interest in co-design reflects this emerging sentiment.

While understanding user needs might seem obvious to those in the design community, the concept of engaging patients in the design of healthcare has gained prominence only in recent years.[42] Accompanying this rise in interest to engage patients is the proliferation of "patient advisory councils" across the system, allowing patients and their families an unprecedented opportunity to share experiences and offer advice on all sorts of issues. While this is undoubtedly a positive development for a system traditionally driven by providers, there is also the danger that these engagement processes might intentionally or unintentionally exclude the voices of certain segments of the population, particularly those from marginalized and vulnerable groups. Often the patients we need to hear from the most are the hardest to reach. There are many reasons why patients from certain segments of the population might be excluded from engagement activities:

- We might have limited time and resources to engage patients, and it's easier to just engage patients or groups with whom we are familiar

- We don't have established relationships with or access to patients from marginalized and vulnerable groups

- We might be worried that if we engaged one group, we have to engage all other groups, which will crush our design process

- We might be afraid that our plans will get derailed by groups with extreme demands

- We invite people representing marginalized and vulnerable groups, but they don't show up because there are barriers to participation (e.g. some people simply don't have the luxury of taking time off work attend a meeting or focus group if it is scheduled during working hours, or those with mobility limitations might be deterred by the inaccessible location or venue where the meeting is held)

Designers working in healthcare know that they must overcome these challenges in order to achieve meaningful engagement and co-design with patients. However, in practice, one often feels that this goal is in conflict with pragmatic considerations such as rapid project timelines, limited resources, or the need to contain project scope.[43] This can lead to solutions that miss the mark for those with exceptional needs and perpetuate inequities.

DESIGN GALLERY

Many of the products and services that are commonplace around us were originally designed for/by users with exceptional needs. This chapter is a curated gallery of some of the innovations that have successfully made the journey from the fringes to the mainstream.

THE MOUNTAIN BIKE

Originator: Off-road cycling enthusiasts in Northern California

In the 1970s, a group of enthusiasts began modifying road bikes so that they could ride down the rugged hillsides of Mount Tamalpais in Northern California. Successive modifications, driven by competition for who could get down the mountain fastest, gave birth to the modern day mountain bike, including a rigid frame, fat tires, heavy-duty brakes, etc. Since those early days, the mountain bike has moved from a niche to mainstream vehicle, used not just for off-road purposes.

Image 06:
Art Black and the Upper Reaches of Repack.
Wende Cragg, October 1978.

OXO GOOD GRIPS

Originator: Sam Farber / OXO

Farber's wife had difficulty gripping ordinary kitchen tools due to a slight case of arthritis in her hands. Farber saw the opportunity to create more comfortable cooking tools to meet the needs of users like his wife, and eventually all types of users.

Image 08:
Observation Hill.
Gaelen Marsden,
November 20, 2006.

Image 09:
Haifa Crosswalk.
David Shankbone,
December 2007.

CANADA GOOSE

Originator: Sam Tick

Canada Goose initially manufactured custom down-filled coats and heavy-duty parkas for the Canadian Rangers in the arctic and police forces across the country. Today, Canada Goose parkas are worn by large segments of the general population.

CURB CUTS

Originator: Jack H. Fisher

In 1945, army veteran Fisher, then a disability rights lawyer, petitioned the city of Kalamazoo, Michigan to cut the curbs so that disabled veterans with mobility aides (wheelchairs, prosthesis) could easily and safely cross the streets. Curb cuts are now ubiquitous, and benefit just about everybody, from mothers with baby carriages to people with luggage. In the United States, curb cuts became mandatory under the Americans with Disabilities Act in 1992.

Image 10:
Botox To Go.
Frankenschulz,
April 22, 2012.

Image 11:
WVS Hot Meals Service.
Ministry of Information, United
Kingdom, 1942.

BOTOX

Originator: Dr. Jean Carruthers

Botulinum toxin type A (Botox) is a neurotoxin originally developed and approved for use in the treatment of muscle spams. However, Dr. Jean Carruthers, a Canadian ophthalmologist discovered in 1987 that Botox injections could erase wrinkles as easily as they could stop eye spasms. This process is known as off-label use, which is responsible for the development of a large number of pharmaceuticals (as discussed in the previous chapter). Interestingly, although Botox is now the world's most popular cosmetic procedure, Dr. Carruthers does not receive any royalties because she failed to obtain a patent.[44]

MEALS ON WHEELS

Originator: Women's Voluntary Service, Great Britain

Meal delivery to the home originated in Great Britain during the Blitz (bombing by Nazi Germany), when damaged infrastructure made it extremely difficult and dangerous for people to access food supplies and to cook.[45] The Women's Voluntary Service (WVS), a voluntary organization made of up civilian women, delivered food to people in bombed areas. The concept of "Meals on Wheels" grew out of the WVS' work during this period. After World War II, the program evolved to serve homebound seniors and eventually spread to many parts of the world.

MAIN STREAMING

To the extent that achieving mainstream adoption is desirable, this chapter discusses the factors important to that process.

The examples presented in the design gallery are, of course, limited to products and services that have successfully made the journey from fringe to mainstream usage. The reality is that the "mainstreaming" process is often fraught with unexpected twists and turns, and luck has a big say on what succeeds and what fails. For every successful example that we are aware of, there might be many more that never made it out of their initial niches.
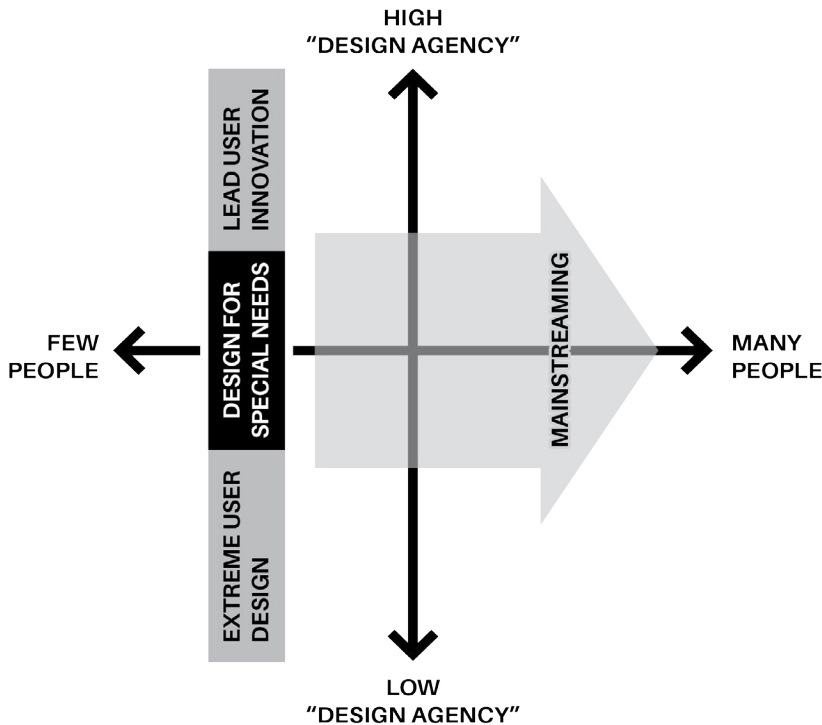
Figure 05:
Mainstreaming

DIFFUSION THEORY

Diffusion studies by Everett Rogers tell us that the spread of innovation – from *innovators* to *early adopters, early majority, late majority* and eventually *laggards* – depends on many things going right simultaneously, much of which has to do with the characteristics of the innovation, as well as the complex interactions between people and their social systems.[46]

Rogers identified five characteristics of innovations that explain their pace of adoption:[47]

1 **Relative advantage ·** degree to which an innovation is perceived as better than the idea it supersedes

2 **Compatibility ·** degree to which an innovation is perceived as being consistent with existing values, past experiences, and needs of potential adopters

3 **Complexity ·** degree to which an innovation is perceived to be difficult to understand and use

4 **Trialability ·** degree to which an innovation may be experimented with on a limited basis

5 **Observability ·** degree to which the results of an innovation are visible to others[46]

Many of these factors are obviously outside the control of the designer. However, *complexity* is a characteristic the designer can have the most influence over. Generally speaking, complex innovations are more difficult to diffuse than simple ones, all else being equal. This is because simple innovations are much more amenable to *re-invention*. According to Rogers, adopting an innovation is not always a passive process of implementing a new idea as-is.[48] Many adopters want to participate actively in modifying an innovation to fit their unique needs. This means being able to know how it works and tinkering with its mechanisms and features; the more complex it is, the less amenable it is to this process. And so the secret to achieving mainstream adoption might be through adaptation.

ROLE OF DESIGN

In the book *Design Meets Disability*, Graham Pullin challenges the notion that products designed for the disability community need to be bland, discrete and unappealing.[49] Hearing aids have gotten smaller and smaller in an effort to conceal the wearer's "impairment", even though larger versions offer superior performance. Prostheses are molded from pink plastic in an attempt to camouflage them against the skin, and so on. In contrast, eyewear is no longer considered a visual aid it once was, in the same way hearing aids are today; they have become fashion accessories and part of mainstream culture, with little or no social stigma attached. Why is that?

According to Pullin, uninspiring, medical-looking devices are the way they are because the medical engineers who develop them are often obsessed with fulfilling functional requirements of the target user, often at the expense of addressing other needs, which might be more universal. For instance, people with visual impairment might share some needs with those without the impairment, and to appeal to both groups, a design would need to appeal to that shared need. He calls this "resonant design". That is to say glasses or spectacles are not just about the need to see, but the need to be seen, as a matter of personal identity, style and how it makes one feel. These are the sorts of transcending qualities that allow a design to go mainstream. Through greater interdisciplinary collaboration between the medical and design communities, Pullin argues, we have the opportunity to create solutions that embody both technical brilliance and considered design that inspire their use.

ROLE OF INTELLECTUAL PROPERTY

It is unclear what the role of intellectual property is in the propagation of designs into the mainstream. In the examples of the mountain bike, eyewear and Meals on Wheels, the absence of patent protection certainly helped spawn entire industries in which variety and design variants helped to expand the market well beyond the initial niche. For example, the early designs of the mountain bike enthusiasts in Northern California were quickly copied by major bicycle manufacturers and marketed to the masses.[50] Similarly, the rapid spread of certain open-source software, such as Android, Firefox and Linux, is largely attributed to there being low intellectual property barriers.

However, innovations such as OXO Good Grips, Canada Goose and Botox have strong intellectual property protection and yet, have also been able to achieve mainstream appeal.

ROLE OF STORYTELLING

One of the under-recognized characteristics of products and services designed for/by exceptional users is the powerful narrative behind them. As OXO Good Grips and Canada Goose have shown, their fringe origins can often be their distinguishing characteristic and identity. And mainstream users seem to find that appealing.

Savvy marketers like Dani Reiss, CEO of Canada Goose, understand the value of a good story. In fact, Reiss - an English literature major from Woodsworth College at the University of Toronto - aspired to be a writer and had little interest in taking over the fledgling family business (originally called Metro Sportswear). That all changed shortly after graduation when the young Reiss accompanied his father to a trade show in Europe, where he learned that the "made in Canada" aspect of their product was revered by Europeans.[51] His interest grew further upon discovering that the company's jackets were worn on trekking expeditions to the South Pole and on film shoots for nature documentaries in Siberia. Beyond the functional qualities of the jacket, Reiss had discovered the product's emotional appeal, particularly among those in other countries who view Canada as a place of extreme climate, the kind of place where you'd find a good parka. When Reiss eventually took over the declining family business in 2001 at age 27, he changed its name to Canada Goose and decided to keep 100 percent of the manufacturing in Canada.[52] And that's really when the small, struggling family business took off and became a global powerhouse in outdoor winter wear. Today, despite Canada Goose's mainstream appeal and popularity with A-list celebrities, Reiss never strays from the original narrative, as evidenced by a recent interview in AdWeek:

> "We've been in this business a long time, outfitting everyone from Arctic bush pilots to industrial workers in the coldest places on earth. We don't need to make up stories about our product."[53]

In today's information age, with so much content vying for people's finite attention span, stories that are able to make an emotional connection with the audience are those that are most likely to stick and spread. And so mainstreaming could be as much about the inherent qualities of the innovation as it is about the story behind its origins.

THE PODS CASE STUDY AND CRITICAL REFLECTION

In 2014, I led a project to design a patient-oriented discharge summary (PODS) at UHN OpenLab. The project is presented here as an in-depth case study because of its attempt to bring together many of the concepts described in the preceding chapters. The case study is presented in *critical reflection* format, with descriptive, reflective and critical components.

DESCRIPTION

The Context

The period following discharge from a hospital is a vulnerable time for patients. The transition of care from hospital to community or from hospital staff to patient self-management can result in adverse events leading to avoidable emergency visits, hospitalizations and bad patient outcomes. Poor communication of discharge instructions with patients had been identified as an important care gap, with several possible causes, including: patients not understanding medical terms; patients not being fluent in English; patients not able to memorize verbal instructions; and patients being too stressed at time of illness to absorb information.[54]

Studies have shown that 40-80 percent of the information patients receive is forgotten immediately[55] and nearly half of the information retained is incorrect.[56]

The problem is even more pronounced for patients with language barriers, particularly in ethnically diverse communities such as Toronto, where over 60 percent speak languages other than English or French at home, and 4.5 percent of residents report having no knowledge of either of Canada's official languages.[57] Even for people with no language barrier, the ability to obtain, process and understand basic health information and services needed to make appropriate decisions – known as health literacy – varies from person to person.[58] An estimated 55 percent of Canadians between the ages of 16 and 65 have low health literacy, and only 12 percent of those above the age of 65 have adequate health literacy skills. [59]

The Project

The project set out to create a tool that would help patients facing language barriers and health literacy challenges understand how to manage their care after going home from hospital. But it also aspired to create a tool that, ultimately, mainstream patients would want to use.

The project followed the general design thinking process of the Hasso Plattner Institute of Design at Stanford (D.School), consisting of the following components: emphathize, define, ideate, prototype and test.[60]

The following section describes what we did in each component, with particular emphasis on addressing the needs of exceptional users – those facing language barriers and health literacy challenges.
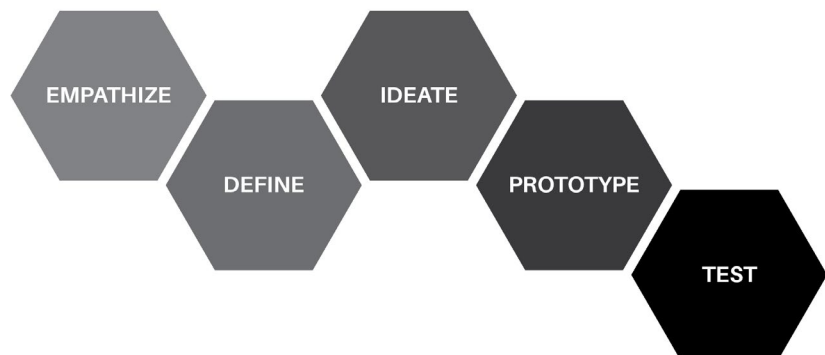
Figure 06:
Design Thinking Process.
Stanford d.school.[32]

Image 12:
PODS Cultural Probe,
Disposable Cameras.
Tai M. Huynh,
December 3, 2013
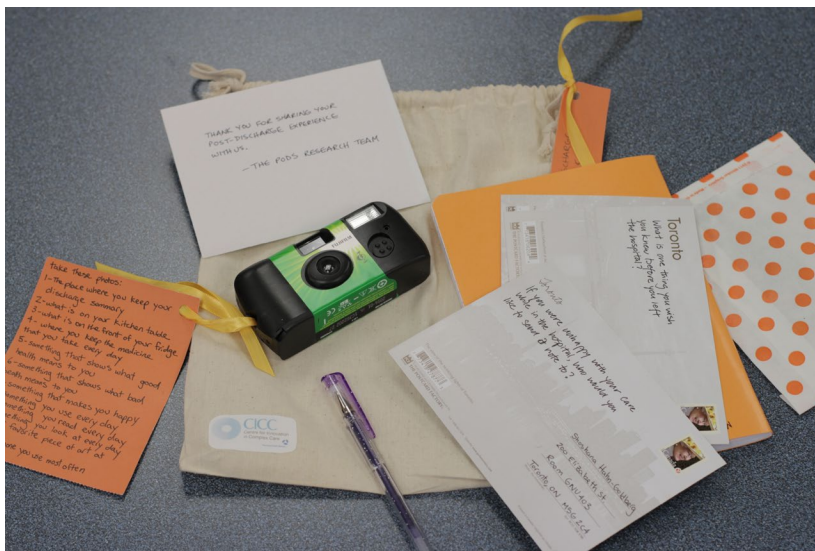
Image 13:
PODS Cultural Probe,
One Complete Kit.
Tai M. Huynh,
December 3, 2013

Empathize

We observed patients in the clinical setting during hospital discharge. Select patients with mild language barriers or perceived health literacy challenges were given a take-home information collection kit known as a *cultural probe*,[61] consisting of a personal journal, disposable camera and 'postcards from home' to document their post-discharge life. The *cultural probe* provided the team with a window into how discharge information might be used in the real-world context when patients arrive home.

Here's a sample of a journal entry:

> "What a terrible start to the day. (My husband) has his own agenda of what I should and should not be doing. Here again instructions from the hospital would have been helpful. Cross words have been spoken and I know neither of us is at fault. I seem to cry very easily."

Define

We reviewed the types of information patients are currently given at discharge across several hospitals in Toronto. In our review of discharge summaries from different hospitals, it was evident that these were information dense documents laden with technical language meant mostly for the patient's primary care provider. These documents were not well suited for use as tools to transmit critical information from hospital to patient at time of discharge. In the world of discharge summaries, patients are almost thought of as messengers in the transport of documents from hospital to primary care provider, a practice also performed by fax machines. Given that the hospital discharge event and ensuing primary care appointment might be separated by many days, this practice seemed less than ideal for assisting patients in self-management. Even for patients who do not face language barriers and health literacy challenges, these documents would be difficult to understand.

In terms of content, patients didn't necessarily want to know everything in the traditional discharge summary, just the information that was relevant to them and that they could act on. They consistently mentioned the following types

of information as being most important, which clinicians working on our team concurred with:

- Medication instructions

- Follow up appointments with phone numbers

- Normal expected symptoms, danger signs, and what to do

- Lifestyle changes and when to resume activities

- Information and resources to have handy

Ideate

Inspired by the extreme user research approach, we conducted an "extreme literature review" targeting developing countries, particularly those with low literacy rates or large numbers of spoken languages. The purpose of this literature review was to see how people in extreme environments communicate health information, both as a source of ideas and inspiration for our project. Countries like India intrigued us because its national census indicates a total of 122 languages in use among its people.[62] Similarly, in South Africa, there are 11 languages that are spoken by at least one million people.[63] Countries like Pakistan interested us because at 55 percent, its adult literacy rate is among the lowest in the world.[64] Targeting our literature searches at these counties, we found some pretty interesting solutions. For instance, in countries such as India, South Africa and Pakistan, there is heavy use pictograms in discharge forms and medication instructions, which have been shown to increase patient understanding and compliance with care instructions.[65,66,67] For example, at the Kasturba Hospital in Manipal, India, a group of researchers used pictograms to communicate information about the adverse effects of antiretroviral (ARV) therapy used to treat HIV/AIDS, particularly among those with low literacy. The team designed a set of 20 simple, culturally sensitive pictograms of adverse drug reactions to ARV. They interviewed 50 hospitalized HIV positive patients on ARV therapy who ranged from having no schooling to college level education. Results from their study suggest that the use of pictograms can be effective as a counseling tool to improve patient's knowledge towards the side effects of ARV therapy, particularly among low literacy patients, as well as improve self-efficacy to deal with the challenges associated with adherence to their ARV management.[68]

In South Africa, pictograms for prescription medication instructions have been designed, developed and evaluated in regions with a high percentage of people who could not read. In one study, the researchers adopted a multistage, iterative process to design a set of local pictograms to communicate medication information among the Xhosa population in the Eastern Cape - an economically poor region with low literacy rate. The team found that the use of pictograms was more successful over written text drug labels when communicating medication information. The use of pictograms increased accuracy in the understanding of the medication instructions and also enhanced recall. The study concluded that the use of pictograms could be effective, particularly if they are developed in collaboration with the target population and cultural influences are taken into consideration.[69]

The impact of low health literacy affecting accurate understanding of and adherence to discharge medication prescriptions was also recognized as a major challenge at the Services Hospital in Lahore, Pakistan - where nearly half (48 percent) of patients were identified as having low literacy. The study team found that an overwhelming majority (88 to 95 percent) of these illiterate patients struggled to understand the written discharge prescriptions after leaving the hospital. The team redesigned the discharge medication prescription using pictographic images and symbols to convey the information. To evaluate the impact of the redesigned pictorial discharge prescription, the team conducted a pre/post survey with 100 low literacy patients. Findings showed that the redesigned pictorial prescription instructions demonstrated large relative increases in patients' comprehension of their discharge medication. Specifically, results indicated that 23 to 35 percent of the participants (depending on the level of counselling given) understood their medication discharge instructions compared to 5 to 12 percent in the group where only text written instructions were provided.[70]

We then ran a co-design workshop where we invited a number of patients, health care providers and designers who worked in teams to ideate around what PODS could be. Each team was given a different patient *persona* to work from, each with a distinct clinical condition and home environment, and varying levels of language proficiency and health literacy.

Image 14:
PODS Co-Design Workshop.
Tai M. Huynh, February 2014.

Image 15:
PODS Co-Design Workshop,
Team Presentation.
Tai M. Huynh, February 2014.

Prototype

Based on the ideas generation during the co-design workshop, a PODS prototype was developed. In designing PODS, we also gave careful consideration to the existing body of knowledge and best practices surrounding the effective design of patient education tools and materials. Visual aids have been shown to be particularly useful to non-English speakers and patients with low health literacy, who tend to have poorer recall of medications and instructions.[71] It is also known that written materials are more effective when they are simple, use larger fonts, and focus on essential information.[72] It also helpful to use short words and sentences, writing directly to the reader, listing important points in list format, and using left justification so there is even spacing between words. An illustrated medication schedule has also been shown to be effective.[73]

In addition, the prototype PODS also gives consideration to the cognitive processes involved in information processing and retention by including white space in the margin for patients to jot down their own notes, which has been found to improve information recall.[74] This also allows patients to record information in their own words, in whatever language they are most familiar with.

Test

Prototype 1 was tested with several groups of patients, along a spectrum of abilities:

Patients facing language barriers • we ran a focus group with Cantonese-speaking patients and family members at the Toronto Western Hospital where we presented Prototype 1 and asked for feedback; this process was conducted with the help of a language interpreter.

Patients who might be challenged by health literacy • we ran a focus group with mental health patients at Toronto General Hospital where we presented Prototype 1 and asked for feedback.

Communication savvy patients • to enhance the mainstreaming potential of PODS, and look for *resonant design* opportunities, we solicited feedback from the UHN virtual patient panel, an online group consisting of patients and former patients of UHN.

Patient feedback from these processes led to changes and further refinements, encapsulated in Prototype 2 seen below.

Understanding the shortcomings of focus group testing, and the need to test the prototype within the real-world clinical setting, we conducted a usability test of Prototype 2 across three large academic hospitals, where physicians and residents in general internal medicine units filled out the PODS by hand for each patient discharged. We then solicited feedback from the clinicians as well as patients who received the prototype. This led to further changes and refinements, resulting in Prototype 3. This version of PODS was then translated into the 15 most common languages spoken by patients in Toronto.

For more information on PODS, visit: pods-toolkit.uhnopenlab.ca

Name _____   Date _____

WHAT HAPPENED AT THE HOSPITAL

My medical problem	Tests I was given	People on my care team

WHAT TO EXPECT WHEN I AM AT HOME

🖐 Medications I need to take

Medication: What it is for	☀	☀️	🌤	🌙

📅 Follow-ups I need to have

I have a booked appointment to see: _____ on ___/___/___ at ___:___ am/pm
located at _____ #_____

☺ What symptoms I should expect and what to do

Symptom	What to do

Normal / *Danger*

🚶 When to resume my activities

Activity	When to resume

☎ Resources available to me

For _____ call _____ or go to_____
For _____ call _____ or go to_____

Figure 07:
*PODS Prototype,
Version 1.*
UHN OpenLab, 2014.

_____'s Care Guide

I came to hospital on___/___/___and left on___/___/___

I came in because I have_____

✏ *my own notes*

Medications I need to take

Name	What it is for	morning	noon	afternoon	night
		☐	☐	☐	☐
		☐	☐	☐	☐
		☐	☐	☐	☐
		☐	☐	☐	☐

How I might feel and what to do

I might feel	What to do	Go to Emergency if:

Changes to my routine

Activity *(i.e. dietary, physical)*	Instruction

Appointments I have to go to

Go see_____for_____on ___/___/___ at ___:___ am/pm

Location:_____ ☎ _____ ☐ booked

Where to go for more information

For medication instructions call/go to pharmacist ☎ _____

For_____call/go to_____ ☎ _____

Figure 08:
*PODS Prototype,
Version 2.*
UHN OpenLab, 2014.

_____'s Care Guide

I came to hospital on dd/mm/yy and left on dd/mm/yy

my own notes

I came in because I have_____

Medications I need to take

Name	Dose	What it is for	morning	noon	afternoon	night
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐
			☐	☐	☐	☐

How I might feel and what to do

I might feel	What to do	Go to Emergency if:

Changes to my routine

Activity (i.e. dietary, physical)	Instruction

Appointments I have to go to

Go see_____for_____on dd/mm/yy at oo:oo am/pm

Location:_____ ☎ _____ ☐ booked

Where to go for more information

For medication instructions call/go to pharmacist ☎ _____

For_____call/go to_____ ☎ _____

Figure 09:
*PODS Prototype,
Version 3.*
UHN OpenLab, 2014.

Results

The resulting design was presented to the Toronto Central Local Integration Health Network (TC-LHIN), who funded the project. The TC-LHIN shared PODS with the CEOs of hospitals in the Toronto area, and asked if anyone was interested in putting PODS into practice. The response was very positive. In the end, 8 Toronto-area hospitals volunteered to be early adopters of PODS.

Thanks to the enthusiasm and dedication of the local implementation teams, PODS went live at all sites (a specific department within each early adopter hospital) by April 1, 2015. In the first month alone, over 200 patients across Toronto received PODS during their hospital discharge.

Among patients given PODS across early adopter sites (during the first month of implementation), discharge communication experience was overwhelmingly positive across multiple dimensions. The percent of patients who responded "Agree" or "Strongly Agree" to statements regarding their understanding of discharge instructions was 92 percent .

The average improvement pre- and post-PODS implementation across sites ranged from 9.3 to 19.4 percent. It's worth noting that prior to PODS implementation, these early adopters were already high performers relative to other hospitals. Therefore, we believe improvements could be more marked in hospitals with lower baseline performance.

It is unclear what proportion of patients receiving PODS could be considered "mainstream" patients, versus those who face language barriers or health literacy challenges. It appears that although the original intent of PODS was to address issues for the latter group, hospitals are interested in PODS as a tool for the general patient population.

REFLECTION

Overall, the PODS project was a success in many regards. It targeted a user group with exceptional needs. It involved them throughout the design process. And in the end, the resulting product was also appealing to the mainstream patient population.

This section reflects on the experience, why things went the way they did, the compromises that were made and how I feel about them.

Designing for and with people who face language and health literacy barriers was definitely a challenge. While overall, I was happy with the level of patient engagement throughout the design stages, compromises had to be made in certain areas for pragmatic reasons.

User Engagement • We wanted to establish an intimate familiarity with the lived experience of people with language and health literacy barriers after they arrived home from hospital. This is a world that those designing tools for the hospital setting rarely see and consider, and the *cultural probe* was to be our window into that world. While much insight was gained from the *cultural probe*, its use was limited to only those with mild language difficulties. We chose not to give the *cultural probe* to patients with extreme language difficulties because all of the instructions - written and verbal – as well as the returning journal entries would have required translation, and we simply did not have the budget for that. However, we found other ways to engage with the target users, including two focus group sessions, one involving Cantonese-speaking patients and family members (a translator was brought in for 1.5 hours) and the other involving mental health inpatients.

Costliness of Methods • While we were interested in the employing the *lead user* methodology to collect information about both needs and solutions from "markets that face similar problems in a more extreme form"[75] we were again faced with the pragmatic considerations that necessitated a more low-cost approach. When von Hippel applied the *lead user* methodology at 3M, they used telephone interviews to network their way into contact with *lead users* further and further up the "pyramid of expertise".[76] They eventually traveled to hospitals in Malaysia, Indonesia, Korea, and India to learn how people in extreme environments keep infections from spreading in the operating room.[77] This was not possible with our limited project resources. While still being interested in solutions devised by those in more extreme environments, we opted to conduct a targeted literature review geared at identifying innovative health communication practices in developing countries with low literacy rates or large numbers of spoken languages. This *extreme literature review*, while yielding nowhere near the amount of information of von Hippel's technique at 3M, was sufficiently informative and provided a good return on effort for the PODS project, and the findings also served as a source of inspiration for the PODS team and helped team members envision what might be possible for PODS.

Local Adaptation • Despite the significant effort on the part of our team to design PODS down to the finest of details, each early adopter site ultimately modified PODS to suit their local needs and circumstances. However, many of these derivatives of PODS still retained the essential content and layout of the initial design. The area of widest variability was the process by which PODS was completed and given to patients. At most sites, PODS was filled out by members of the clinical team while at one site, it was patients and their family who filled it out themselves. Even among sites where PODS was filled out by clinical staff, who actually filled it out varied from hospital to hospital. This is because the role of discharge communication rests with different members of the clinical team, depending on the hospital, and some hospitals employ dedicated discharge coordinators, while others do not. Moreover, some sites implemented PODS as a paper-based form, while others implemented it as a tool within their electronic system.

The tinkering and re-invention observed among the PODS early adopters is an important part of the mainstreaming process, something that diffusion scholars like Rogers previously articulated.[78] In spite of this, in healthcare, there is a tendency towards devising complex interventions that, if proven effective (say in a randomized-controlled trial), can be difficult to replicate in different environments under different conditions. In contrast, PODS is a relatively simple solution that could be easily modified by people in different environments, which enhances its diffusion potential. Don Berwick, founder of the US-based Institute for Healthcare Improvement, once remarked "Individuals who develop an innovation often are not its best salespeople, because they usually are at least as invested in its complexity as in its elegance. They tend to insist on absolute replication, not adaptation."[79] PODS demonstrates that the secret to achieving mainstream adoption might be through adaptation.

CRITIQUE

Is it enough to design PODS for those with language and health literacy difficulties? Or is there more to be gained? This section takes a critical view on the PODS experience and attempts to derive new meaning for the *design by exception* approach.

Although PODS was initially intended to help patients with language and health literacy challenges, we recognized its mainstream potential from the beginning

and took steps help broaden its appeal. For example, in addition to running focus groups with Cantonese-speaking as well as mental health patients, we solicited feedback from the UHN virtual patient panel, an online group consisting of communication savvy patients. And our usability test of Prototype 2 involved patients with varying abilities. This is unlike what happened with the mountain bike, curb cuts or Meals on Wheels, where the designers were focused exclusively on meeting the needs of the initial narrow band of exceptional users they were targeting. Giving consideration to mainstream usage this early in the process had its pluses and minuses, of course. On the one hand, the rapid uptake of PODS might have had something to do with the fact that some aspects of its design (e.g. simple and clean layout) are universally appealing, while other aspects are mindful of the needs of exceptional users (e.g. large serif fonts, high contrast, written in the first person). On the other hand, it is unclear whether the original intended users of PODS – those with language and health literacy difficulties – would find the final PODS product too watered down for their needs. For example, while the PODS template is available in 15 different languages, clinicians are likely to use the English version if that is the only language they can communicate in. We have yet to create a solution that couples languages (e.g. English and Cantonese, English and Tamil, etc.) such that both the clinician and patient (with the help of an interpreter if necessary) can both be comfortable interacting with.

Unfortunately, the patient experience survey data collected does not include respondent characteristics such as language and health literacy aptitudes to allow us to assess its effectiveness for this population. This is a limitation in our measurement methods that we hope to address through future research.

If PODS proves to be a useful tool for exceptional and mainstream users alike, then the PODS project would be an overall success and we might be able to say that *design by exception* lives up to its promise. But if it is helpful to mainstream users (which the early data appear to suggest), but fails those it was originally intended to serve (we shall see), then the PODS project would, in my opinion, be a failure. This is because it is not enough to improve care for the mainstream population, especially at the expense of those who are marginalized. Doing so would effectively equate to exploiting outliers and extreme users for important information so that we can design better products and services for everyone else, which is a moral quandary we should avoid at all cost.

CON CLUSION

In concept, the *design by exception* philosophy makes intuitive sense, and there are plenty of examples of innovations around us to suggest that when we design products and services for exceptional users, everyone benefits. If this were indeed the case, however, then it would seem sensible for every designer working in healthcare to adopt this philosophy. It has the promise of improving health equity for some and raising the bar for all. Moreover, given that there is a small number of patients who are poorly served by the current system that drive most of healthcare costs (5 percent of patients consume 65 percent of all healthcare resources),[80] there is arguably a fiscal imperative to move in this direction as well.

However, as a practiced design approach, there is still a lot we don't know about *design by exception*. These unanswered questions fall into three broad categories, and represent areas for future development that I (and perhaps others) would like to pursue:

Methods • In the design of PODS, we saw that certain *lead user* methods described by von Hippel for the industrial setting were simply far too expensive to conduct in a budget-conscious healthcare environment. As a result, cheaper

methods had to be devised as more feasible analogs. It would be interesting to see what new methods might emerge from combining the *design by exception* way of thinking with methods already in wide use in healthcare. An example of this was the *extreme literature review* conducted as part of the PODS project. These types of mashups in methods will help tailor the approach for the healthcare environment and increase uptake.

Diversity of Application • In this paper, PODS was presented as a case study in which several of the concepts that underlie *design by exception* were put into practice. However, further experimentation is needed with the overall approach across a wide array of issues and broad spectrum of users.

Evaluation • In healthcare, with its deep tradition of evidence-based decision-making, it is simply not enough to put forward a new idea. For *design by exception* to gain acceptance, it must be able to demonstrate, with convincing evidence that it works and preferably, across diverse genres of problems. Accordingly, its application should, where possible, be coupled with the collection of data that can speak to whether or not it has made an impact.

Now, stepping back for a moment, it is clear that while we don't yet have enough evidence to show that *design by exception* works, we know for a fact that the "one size fits all" approach that is so pervasive in healthcare doesn't work, and often marginalizes the people most in need. The latter tends to view users with exceptional needs as outliers and misfits who can quickly complicate our work, while *design by exception* challenges us to embrace these users as sources of immense insights and inspiration, as people to be sought after rather than ignored or accommodated. And given that Canadians - who have long considered Medicare among their most cherished of institutions - are now showing a strong appetite for overhauling the current approaches, designing for and with exceptional users might just be the antidote to what's ailing healthcare.

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