



The Divergency Model: UX Research for and with Stigmatized and Idiosyncratic Populations

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Abstract. In UX research, people with idiosyncratic or stigmatized conditions may go unrecognized, be dismissed as outliers, or be lumped within the larger normative group. This most directly affects persons with disabilities, medical conditions, or differing lifestyle or belief systems. This tendency may over represent the homogenous group while under representing other idiosyncratic groups based on complex factors such as stigma or perceived risk associated with revealing more accurate aspects of conditions, beliefs or lifestyle. This research bias negatively impacts the outcomes of the UX data and impacts the quality of designed products or services. Therefore, there is a critical need to identify the roles of ethnographic research, cultural programming, and cultural relativism with regard to stigmatized and idiosyncratic populations. The Divergency Model is a UX research and design methodology to identify and measure proximal distances in stigma/conformity and apathy/motivation between individual or target groups.

Keywords: UX · Research · Disabilities · Stigma · The Divergency Model
The Connectivity Model · Ethnographic research

1 Introduction a Subsection Sample

The ability to adequately understand the cognitive, social, emotional, motivational and behavioral tendencies of a target audience are the important underpinnings of user experience (UX) research and design. However, not all members of a target audience are equally willing or able to participate in all forms of UX research. People with disabilities and mental illness are often subject to high levels of stigma by society. In healthcare, stigma is considered to be one of the biggest obstacles in their care and quality of life (Sartorius 2007). The target audience may believe that they either are not able to adequately perform the necessary tasks because of idiosyncratic skills or beliefs or because they believe that their participation would put them in a position of significant personal risk due to disabilities or stigmatizing beliefs or conditions. In addition, failing to include all members of the target audience because of disability or stigma can introduce significant bias into the research due to oversampling of normative populations and under-sampling of idiosyncratic, atypical, or outlier populations. Therefore,

there is a critical need to develop an assessment tool for UX researchers to evaluate levels of stigma or proximal idiosyncratic responses in target audiences for the purpose of more robust risk management and mitigation strategies to improve inclusion and accurate representation in their research.

2 UX Research

User participatory design research tools such as usability tests, surveys, focus groups, biofeedback, ethnographic observation, eye tracking, and other types of user testing are widely accepted strategies for informing research-based design. However, typical user testing strategies and procedures often require the participant to have at least a basic command of spoken language, written language, and cognitive skills. There is also the basic assumption that the participant can freely offer their input in unbiased and uninhibited ways and consistent ways without fear of retribution, judgement, or a negative impact. However, many members of society may not fit this typical, homogenous user profile either temporarily or a continuous basis. These nonhomogeneous, atypical and marginalized user groups are a critical consideration in the design of spaces, products and communities designed specifically to serve their unique needs. Factors such as levels of conformity or stigma and motivation or apathy can impact a target audience's willingness and enthusiasm for meaningful participation in user experience design research. Therefore, there is a critical need to understand the roles of conformity and motivation with regard to target audiences.

Good design assumes that the designer and the user have a common language and a common set of expectations that are achieved through the designer's conceptual model and interpreted through the user's mental model. According to Donald Norman, a good conceptual model allows the designer to predict the actions of the user. Mental models are the cognitive constructs that people have of themselves, others, the environment, and things with which they interact (Norman 2016). Therefore, when a target audience has unique, divergent or idiosyncratic ways in they experience and interact with the world through social, emotional, physical, behavioral, or motivational channels, the designer must have a way of interpreting and measuring the ability of their conceptual models to meet those needs.

3 Cultural Relativism

Dealing with differences in the way individuals think, feel, and act is based in our mental programming. According to Hofstede and Hofstede, this cultural programming is learned in childhood through the social environment and through a person's collected life experiences. When these experiences vary in how they are collected, understood or interpreted, one person's mental programming can be vastly different from another person's even when they are members of the same society or family. This is also influenced by personality which is the unique set of mental programs possessed by an individual that can't be shared with any other human being (Hofstede and Hofstede 2005). Therefore, there is a critical need for a decision-making model that accommodates idiosyncratic populations in UX and UI research and design.

4 Ethnographic Research in UX

Ethnographic research can be an important strategy for working with target audiences where alternate methods of data collection are needed. For persons with language or cognitive impairment or persons with a high level of stigma, a nonverbal strategy for observation and data collection is useful because it can be used without causing stress to the audience. The Connectivity Model is a method for observing, collecting, and analyzing ethnographic data based on social, emotional, physical and behavioral (SEPB) categories. The Connectivity Model is particularly effective for use with populations where direct contact, focus groups, or interviews are not possible (Satterfield et al. 2016). According to a 2015 survey, persons with autism showed preference for lower interpersonal interaction than typical peers (Satterfield et al. 2016). Therefore, by using a non-verbal strategy, persons with language disabilities can still provide valuable data to inform the research with causing them any unnecessary duress.

5 Defining Disabilities

With regard to disabilities, our language and ability to understand and quantify the personal experiences of ourselves or someone else can defy our ability to coalesce them into a normative and homogenous population group as is often done in user experience design. The concept of disabilities is inherently vague and incomplete in terms of how it informs another person about the relevance, significance and impact of the idiosyncratic experience of the disabled person.

Disabilities tend to be defined by society based on a perceived comparison to the abilities of a healthy person. However, in many instances, the disabled person may find their condition either to be quite normal or quite impairing depending on the context of a situation. This may be further complicated by what are considered to be invisible disabilities such as language or cognitive conditions or highly visible physical conditions that are considered to be unacceptable or uncomfortable by individuals or society. Barriers such as a stigmatizing physical appearance, atypical language modalities, or unconventional cognitive abilities have traditionally prevented participation in usability and experience design research. This is in part due to complications in how to involve these user groups and the additional legal requirements as indicated by ethical IRB practices.

6 Designing for Disabilities

According to Pullin, “The priority for design for disability has traditionally been to enable, while attracting as little attention as possible... the approach has been less about projecting a positive image than about trying not to project an image at all” (Pullin and Higginbotham 2010). This emphasis on fixing or improving a person rather than meeting a desirability expectation radically changes the nature of both design research and the designed product. In addition, because of disability related differences in physiological and psychological experiences, the learned cultural aspects of persons

with disabilities may diverge greatly from normative expectations. In addition, design for disabilities has focused more on drawing attention away from the disability than on creating value or desire for the person using the design. According to Pullin, “Design for disability has traditionally sought to avoid drawing any further unwelcome attention to the disabilities it addresses by trying to be discreet and uncontroversial, unseen or at least not remarked on. Disability can still be a source of discrimination and stigma for many disabled people, whereas a minority of medical engineers and designers are disabled themselves. Designing for and with people whose experiences they will probably never share can heighten sensitivity toward inadvertently causing offence” (Pullin and Higginbotham 2010).

7 Usability Studies and Population/Participant Selection Criteria

An initial literature search for research relating to usability studies participant selection, resulted in very little research and writing on the process of, or guidelines for, the selection process. Currently, normative practitioners rely on the business unit to define the target audience and/or developed personas to include in the study as research participants. These methods can introduce bias into the testing results by eliminating or under representing specific user groups or over representing specific user groups. These biases may be based on each group’s ability to perform the test, their ability to comply with the research requirements; a group’s lack of willingness to participate based on anxiety, a group’s predisposition to lie or please the researcher, or based on the researcher’s convenient access to one group over another group. The target audience’s own perception of themselves and their situation may differ from the perception of the same person and situation as identified from a researcher’s point of view.

Very little literature exists with regard to selecting participants, especially from marginalized populations; however, Rubin states “the selection and acquisition of participants whose background and abilities are representative of your products’ intended user is a crucial element of the testing process” (Rubin and Chisnell 2008). Moreover, “Selecting participants involves identifying and describing the relevant behavior, skills, and knowledge of the person(s) who will use your product. This description is known as the user profile...” (Rubin and Chisnell 2008). Finally, “... your test results will only be valid if the people who participate are typical users of the product, or as close to that criterion as possible” (Rubin and Chisnell 2008). We, as practitioners, must strive to be as inclusive as possible when selecting participants for usability testing in any given system. We also must consider guidelines for inclusion and selection of marginalized populations to ensure our system is of greater use to more members of our initially identified audience, as well as marginalized audience members who may otherwise go unnoticed in persona development, especially by the business and marketing units.

8 The Role of Culture and Shared Experience

According to Hofstede and Hofstede, refers to mental programming which is divided into three levels: human nature which is the universal and inherited component; culture which is the learned component shared by a group or category of people; and the idiosyncratic level of personality which is both learned and inherited. Culture is a collective experience or phenomenon that is partly shared with people from the same social environment. Human nature is what all human share. Cultural differences manifest themselves in the areas of what Hofstede calls symbols, heroes, rituals, and values (Hofstede and Hofstede 2005). Therefore, a person may share traits or be a member of multiple cultures based on the person's ability to learn cultural traits. While at the same time they may differ greatly in other areas based on physical, cognitive, social, emotional or behavioral characteristics based on their personality and their unique physiological and psychological makeup.

Therefore, people who align closely with their cultural and with the common traits of human nature are most easily accounted for in user experience design research. Those people who exhibit strong personality traits or traits that are not closely aligned with their expected culture or human nature need to be addressed specifically in user experience design when they will be part of the target user group. Cultural relativism says that one culture has no absolute criteria for judging the activities of another culture or assigning them norms or mores (Hofstede and Hofstede 2005).

9 Measuring Stigma and Motivation Using the Divergency Model

In order to better understand the roles of stigma and motivation, The Divergency Model was created to evaluate the relative similarity or difference from the cultural norm. The center of the diagram represents a neutral position between unmotivated and motivated by a stimuli on the x axis and conformative and stigmatized on the y axis. The farther a target audience or individual moves away from center the more polarized their situation becomes toward motivation and desire versus stigma and apathy. The Divergency Model can be used to quantify an individual respondent within a context or the proximity between multiple respondents with regard their relative levels of conformity and motivation.

The Divergency model combines the motivation to conformity levels of a target audience with regard to a specific situation or stimuli. It identifies stigma and apathy as opposed to comfort and desire. Two or more groups or individuals can be plotted for the purpose of comparing their proximal distance from each other or from the normative population. High Motivation and conformity indicate high desirability and pleasure. Low motivation and stigma indicate low desirability and aversion. The center is neutral in both motivation and conformity (See Fig. 1, and Table 1).

The research survey tool that maps into this chart is based on The Connectivity Model areas of social, emotional, physical, behavioral, and motivational. The horizontal x-axis is the value derived from motivational questions and the survey answers

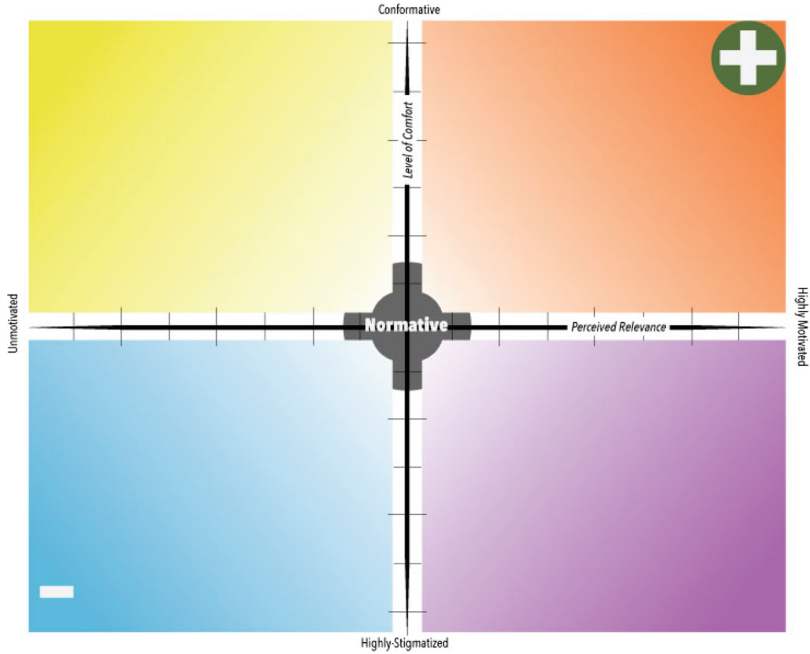


Fig. 1. The Divergency Model

Table 1. The Divergency Model key

ORANGE (Upper right quadrant)	<u>High conformity + High motivation</u> – likely to be pleasurable or desirable, most desirable
PURPLE (Lower right quadrant)	<u>High motivation + High stigma</u> – likely to be acceptable if conformity can exceed stigma or stigma can be reduced or neutralized, desirable but with anxiety barriers
BLUE (Lower left quadrant)	<u>Unmotivated + High stigma</u> – likely to be undesirable or avoided, least desirable
YELLOW (Upper left quadrant)	<u>Unmotivated + Confirmative</u> – likely to be acceptable if motivation can be raised, lacks desire or motivation but resonates with the user

to questions of social, emotional, physical and behavioral (SEPB) questions plot into the y-axis indicating levels of comfort or stigma associated with SEPB questions relevant or descriptive of the situational context of the UX/UI artifact under evaluation.

Low stigmatization is associated with conformity with the typical user group associated with this situation and low level social, emotional, or physical barriers. High Stigmatization is associated with a high lack of conformity with the typical user group associated with this situation and a significant combination of social, emotional, or physical barriers.

Low Motivation is associated with a lack of interest in the situation being evaluated without regard to the suitability of the situation in terms of social, emotional or physical barriers. Low motivation increases the likelihood of that a situation will be mastered or accepted. High Motivation is associated with a high level of interest in the situation without regard to the suitability of the situation in terms of social, emotional, or physical barriers. High motivation can increase the likelihood that a situation will be mastered or accepted.

10 Conclusion

Understanding the roles of stigma and motivation can help UX researchers include more people in user experience design research. By identifying which participants are experiencing high stigma or low motivation can help researchers mitigate the impact of these factors. By including idiosyncratic and stigmatized target audiences effectively into UX research, a better balance of under-represented audiences can be achieved.

The Divergency Model is used to identify people with idiosyncratic or stigmatized conditions that might otherwise go unrecognized, be dismissed as outliers, or be lumped within the larger normative group. It specifically addresses persons disabilities, medical conditions, or differing lifestyle or belief systems. This purpose of The Divergency Model is to address the tendency to over represent homogenous user groups while under representing or dismissing other idiosyncratic groups based on factors such as stigma or perceived risk associated with revealing more accurate aspects of conditions, beliefs or lifestyles. The Divergency Model also addresses inherent bias that is introduced when significantly different user groups are not represented. This in turn negatively impacts the outcomes of the UX data and the quality of designed products or services. Therefore, identifying the roles of ethnographic research, cultural programming, and cultural relativism with regard to stigmatized and idiosyncratic populations is critical to UX research. The Divergency Model also measures proximal distances in stigma/conformity and apathy/motivation between individual or target groups therefore representing the inherent diversity in user groups for any product or service.

11 Areas for Future Research

Future research will include testing The Divergency Model with idiosyncratic and stigmatized populations by developing a set of survey questions to plot into the conformity versus motivation quadrants. The following will be researched:

Idiosyncratic Populations in Usability Studies

Non-homogenous and Idiosyncratic Populations (Identifying them)

- Minority/Cultural/Ethnographic/Racial
- Cognitive/Brain Injury/Neurologically atypical
- ASD

Stigmatized Populations in Usability Studies

- Stigmatized/Marginalized populations
- IRB Protected Populations (prisoners, minors (younger than 18), experiencing diminished capacity, mentally or physically challenged, pregnant (particularly for those projects where physical procedures, exercises, etc., will be performed)
- LGBTQ+
- Mental Illness (Depression/anxiety/bipolar)
- Anxiety that is induced by contexts such as a test

Medical Populations with Disabilities and Stigma in Usability Studies

- Epilepsy
- Diabetes
- MR
- Alzheimer's Disease
- Down's Syndrome
- Dyslexia
- HIV/AIDS

User Participatory Strategies: (Categorize These Based on Required Skills)

Linguistic-Based Taxonomies

- Card Sorts
- Tree testing
- Interviews,
- Wizard of Oz
- Cognitive walk thru,
- Talk/speak aloud
- Focus Groups
- Surveys

Non-verbal Communication and Biofeedback

- Eye tracking
- Body sensors
- RFID
- Spatial and non-verbal communication strategies and devices

Ethnographic Observation

- Video modeling
- Ethnographic observations
- Design as Theater
- YouTube Libraries

Design UX Research Strategies or Models/Methodologies:

- Grounded Theory Model
- Definition of Emotions (EQ)
- Definition of Cognition (IQ)
- Kansei Engineering
- Connectivity Model
- Coolabilities (Narratives and Projects)
- Activity Theory

Risk Mitigation in UX Research

- Identifying Risk or Perceived Risk
- Identifying Risk Contexts
- Risk Mitigation Strategies
- Inclusion Criteria for Risk Mitigation

Accessibility in UX Research

- Identifying Accessibility in SEPB Categories
- Accessibility in UX Participation
- Accessibility and Risk Mitigation

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