## <u>Academic Statement of Purpose</u> PhD in Information Science Nadia Karizat

Through UMSI's Doctoral Program, I want to advance research in the areas of social computing, human computer interaction (HCI) and health informatics under the advising of Dr. Nazanin Andalibi and/or Dr. Kentaro Toyama. Technology and online social spaces can influence the relationship individuals have with their body through mediating their engagements with their self and other people on and off-line, as well as mediating encounters with algorithms, (mis)information, health resources, etc. This mediation might be of higher or unique consequence for those with stigmatized experiences, such as disordered eating or being a higher weight. I will conduct research guided by the following question: how can we engage with and design technology and online social spaces to facilitate a kind, compassionate, and supportive relationship between the body and the self, specifically when a person has endured stigmatized experiences? Having experienced UMSI's interdisciplinary research approach and its faculty instruction and mentorship firsthand as a Master of Health Informatics (MHI) alumna and former Research Experience for Master's Student (REMS) fellow, I am confident pursuing a PhD in Information Science from UM will help me achieve my future research and professional goals of investing my time and energy in interdisciplinary and collaborative research. I want to be a part of a community of scholars that are human-centered and produce knowledge and understandings of phenomena that can help make the world a kinder, more compassionate place.

#### Past Experience: Research Projects

While pursuing my MHI from UMSI, I actively sought experiences to help me acquire the skills necessary to be prepared for doctoral study, such as conducting research, performing analysis and synthesis, and engaging in theory development—the REMS Fellowship at UMSI and my master's thesis are two examples. Through my experiences with the REMS fellowship and master's thesis, I gained hands-on research experience and learned how to manage all components of conducting both collaborative and independent original studies, including designing a study and submitting for IRB approval, recruiting and screening participants, obtaining informed consent, conducting semi-structured interviews, performing open- and axial-coding in a collaborative setting, analyzing qualitative data into themes, writing and preparing manuscripts for submissions to top conference venues like CSCW and

CHI, as well as doing revisions and collaborating with other researchers throughout. It is through these experiences that I've discovered my love and affinity for research.

Through my involvement in the REMS Fellowship program at UMSI, I worked with UMSI's Dr. Nazanin Andalibi, PhD Student Daniel Delmonaco and Carnegie-Mellon's Dr. Motahhare Eslami on a qualitative study involving the social media platform TikTok. Our study contributed to understandings of how users believe algorithms and identity interplay in algorithmic systems, and how algorithmic folk theories shape their behavior on the platform in turn. Our paper, receiving an Honorable Mention award for best paper at CSCW 2021, contributed 3 new concepts: 1) Algorithmic Privilege, 2) Algorithmic Representational Harm and 3) The Identity Strainer Theory. The Identity Strainer Theory is a novel algorithmic folk theory describing when someone believes their social feeds are the result of an algorithm recognizing, classifying, sorting, and suppressing social identities based on its conception of which social identities are (or are not) "valuable" and "wanted", or which ones (do not) deserve visibility. The work featured in our paper demonstrates how perceptions of algorithmic bias and of the algorithm—regardless of whether the perceptions map to what these algorithms technically do—can shape social media platforms and their feeds, such as the case of participants in our study engaging in algorithmic resistance against perceived bias. As algorithms and AI become increasingly ubiquitous, this work details how people rally and resist against the potential harms of sociotechnical systems to achieve their own goals. The findings of this study have fed my interest in understanding how people can be empowered to navigate systems and retain agency when algorithms are becoming increasingly influential. This paper has been assigned in various UMSI courses from the undergraduate to doctoral level taught by Dr. Nazanin Andalibi, Dr. Nicole Ellison, as well as Dr. Oliver Haimson's course where I attended as a guest speaker to discuss the work and answer questions from his students.

Additionally, I completed my Master's thesis, with my advisor Dr. Nazanin Andalibi along with committee member Dr. Kentaro Toyama, where I explored the impacts of producing content about weight-related journeys on social media and the resulting personal digital archive in a society where weight stigma is pervasive. My thesis uncovered a series of positive and negative impacts that returning to past content about one's weight-related journeys had on perceived well-being, such as people experiencing feelings of shame and embarrassment over assessed failure, and others receiving what we dubbed as '*transtemporal support*': support and validation that one receives from their own past content and words, achieved through returning to such past content in the present. This project contributed to understandings of how social media platforms can support individuals engaging with a past that is sensitive or impacted by stigma. My thesis also established weight-related journeys as an instance where researchers can explore the implications of social media as a personal archive when its digital artifacts create a repository of data that may impact one's self-concept and well-being, such as an archive prompting comparisons of the self that attribute one version, past or present, as more worthy. After my thesis was accepted in May, I worked with my advisor over the summer '21 to transform the thesis into a conference paper submitted to CHI '22.

The REMS Fellowship and master's thesis allowed me to conceptualize, design, conduct and analyze two research projects and fueled my passion for research; specifically research that centers people in aims to understand human experiences with technology. I believe my involvement in these projects is one of the reasons I was awarded the Margaret Mann Award at UMSI's 2021 graduation, an award given to those who demonstrate exceptional academic ability and professional promise.

### Past Experience: Coursework

I have also been intentional to maximize my coursework experience to further gain the skills that would bolster my chances for success in a PhD program. My coursework prepared me to be able to gather and synthesize information from various data resources (audio transcripts, databases, tweets pulled from Twitter's API, etc.), conduct semi-structured interviews, analyze qualitative and quantitative data, and prepare these findings to share with others. As part of a semester-long group project for a graduate course called "Contextual Inquiry and Consulting", Dr. Kentaro Toyama instructed the course where I learned user-centered qualitative research methods. As my team's project manager, I supervised and coordinated all aspects of the project from interviewing key stakeholders and interpreting their statements, to analyzing and synthesizing this data through tools like affinity diagrams to identify possible solutions we could present to our client. I have also taken a wide variety of classes in python programming, SQL and databases, statistics, and data manipulation and analysis. As a researcher, my knowledge of python or SQL could help me to quickly process and organize lots of information/data allowing me to, for example, note patterns in a certain survey output based on various respondent criteria. Altogether, these classes prepared me to understand how information and data can be analyzed and understood quantitatively. Becoming a mixed-methods researcher grants me more flexibility with my research approach, such as by giving me the qualitative know-how to retain the voice and experiences of people as shared by participants while also providing the quantitative methods to aggregate large amounts of data to measure potential impact or presence of certain phenomena when ethically appropriate. I am confident that my skills developed through coursework at UMSI will prove valuable in this program, in conjunction with the qualitative research skills I have and hope to continue developing as an aspiring mixed-methods researcher.

## **Future Research Area Methods and Contributions**

I will contribute to research in the areas of social computing, HCI and health informatics. My research aims to be human-centered and understand human behavior, such as understanding the ways people recovering from disordered eating navigate weight-related advertisements or sponsored posts becoming a seemingly ubiquitous part of social media as mediated by AI and platforms that stand to profit off weight stigmatization. While I have experience conducting semi-structured interviews that may serve as a strong foundation to grow my focus group and interviewing skills, I hope to expand my methodology 'tool-kit' to explore the methods of digital ethnography and content analysis to study computer-mediated social interaction. I look forward to learning about ethnographic methods and content analysis as a PhD student because I believe these methods will be important next steps in my research as I hope to observe and analyze human behavior in its organic setting in ethical ways respecting the privacy and integrity of those studied. Having a deeper understanding of these methods would provide valuable insights of the context for where experiences shared by participants in interviews or focus groups occur, as well as offer an unobtrusive closeness to data (e.g. interactions, language, images or sounds on social media).

Beyond these more qualitative methods, I do intend to experiment with other methods that are a good fit for the projects I'm involved in, such as participatory design, survey, and more quantitative methods. As I want to honor my personal commitment to understanding participants as collaborators in research, learning methods like participatory design will provide an opportunity for myself *and* participants to work together on creating a collective vision for whatever technical or social

4

intervention we might propose as part of a study's findings. Through the program's required research methods courses and research projects I collaborate on, I am excited to expand and develop into a mixed methods researcher who is familiar with a wide range of methods and knows which to deploy for any research question I find myself attempting to answer.

### **Future Research Project(s)**

My research is motivated by wanting to learn the ways technology and online social spaces can facilitate kinder relationships between the body and the self, with particular attention to those with stigmatized experiences. My previous research projects have incorporated inquiries into identity and algorithms/AI, as well as impacts of content production of weight-related journeys on young adults. These past projects look at instances where aspects about the self, such as one's identity or weight, are salient to their engagement with technology. While my interests are in improving technology and online social spaces to have positive impacts on well-being for those with stigmatized experiences more broadly (e.g. disability, sexual assault, etc.), I anticipate I will primarily focus on populations subjected to and impacted by weight stigma and disordered eating. In my work, I will move beyond the archetype of thin, white women to include other marginalized or under researched communities within this research space, such as men, gender non-conforming people, and/or Black, Indigenous and People of Color (BIPOC) to understand the ways technology and its engagement with weight stigma, societal beauty standards and disordered eating may uniquely impact these communities.

I propose a series of studies with multiple methods exploring different aspects of my broader research question regarding technology and stigmatized experiences, specifically those involving weight. One multi-year research project I'd like to work on would explore the applications of mobile health (mHealth) technologies affiliated with the weight loss and weight management industry (e.g. *MyFitnessPal, Noom, Kurbo by WW*, etc.), and the ways in which their usage may impact individuals' relationships with their bodies, as well as their personal relationships on and off-line. As weight stigma and fatphobia are pervasive both online and off, and there exists a billion-dollar weight loss and management industry unabashedly profiting off individuals' insecurities with their body weight, I believe there is much at stake and of value to explore within this space to understand the span and

character of the impacts these technologies may have on individuals *and* those in their personal networks, specifically impacts related to stigma, well-being, body image, etc.

One aspect I might explore is intergenerational relationships and attitudes towards weight and engagement with weight-related mHealth applications and social media content. Through interviews or focus groups with parental figures who have encouraged their children to use weight-related mHealth applications and individuals whose parental figures have encouraged them to use these applications, I would like to learn: what is the experience of those who were encouraged to use mHealth weight-loss centric applications by a parental figure(s)? How does a parental figure(s)' understanding of these mHealth technologies and their personal relationship with their bodies shape their personal engagement with these weight-related mHealth applications, and encouragement of these mHealth applications to their children? What impacts does this encouragement have on the child's future relationships with their bodies, usage of weight-related mHealth applications and their relationship with their parental figure(s)? How do the self-reported intentions by the parental figure(s) differ from the self-reported impacts (such as those on well-being or body image) by the child later in life? How does this impact a child's sense of emotional or physical safety? Parental figures can plant seeds of thought and influence children, for better or for worse, with good intentions or not; some of these thoughts might relate to weight and bodies, and may propagate dominant, yet harmful, beliefs filled with weight stigma. By having intergenerational relationships be a feature of this project, I'd allow for the emergence of findings that could point to both technical and social interventions tackling how weight stigma is learned and experienced through personal relationships in the home and online, how this is then potentially mediated by mHealth applications, as well as what influence these experiences may have on one's sense of self, relationship with their body, and relationships with others.

Another aspect I might explore would specifically look at algorithms/AI and advertisements as it pertains to weight and weight stigma. As many of these mHealth applications' sources of revenue are advertisements, I believe a content analysis of messaging in the app's user interface and in the advertisements they allow to be sold on their site might lend itself to understanding ways these technologies may frame themselves as promoting health and well-being but are actually feeding into weight stigmatization, poor body image, increased body dissatisfaction, etc. Building on this, I may look to UMSI's Dr. Sandvig for guidance on how I may conduct an audit to better understand the distribution and consumption of targeted weight-related ads on social media and mHealth applications to gain a clearer understanding of platforms' algorithms/AI system and its relationship with weight and weight stigma, as well as the consequences of operating within that algorithmic system on vulnerable populations. For example, a study learning the experiences and behavior timelines of those who developed an eating disorder while using an mHealth app like *Noom* might ask what role targeted ads had in a person vulnerable to disordered eating downloading a weight-related mHealth application for their personal use. This is of particular interest to me as mHealth applications and social media platforms that generate profit off targeted ads are incentivized for algorithms to direct ads to those who are more likely to 'click.' However, this work would contribute further insight into the post-'click'—what happens well-beyond the time a person clicks on an ad that may stigmatize weight and may promote restrictive dieting, amidst other potentially harmful messages.

Other questions I might ask in this algorithm/AI space may include: How is weight stigma embedded in search algorithms and what are the potential consequences of this on individuals who may use search engines like Google or YouTube as their primary source for finding health information? How do individuals impacted by weight stigma resist perceived algorithmic suppression on social media? What are the ways individuals and communities organize in response to thin women co-opting trends made to celebrate larger bodies (such as those on TikTok), and how do their algorithmic folk theories shape the ways they choose to respond? How does the algorithmic suppression of larger bodies on social media shape the experience of creating content for those who rely on an audience for monetary income (e.g. micro influencers, small businesses, etc.)? Altogether, these are just a few examples of studies reflecting my desire to better understand the relationship between weight and algorithms/AI, and the impacts this might have on individuals' sense of self, experiences with content creation, health-information seeking, etc.

Through these multiple projects deeply investigating questions regarding algorithms/AI, mHealth applications and social media, this body of work will contribute understandings of how to design technology that counters stigma, and specifically how we can build 'compassionate tech' that facilitates a kind, compassionate, and supportive relationship between the body and the self. This work will also contribute to resources that inform and design that supports engagement with mHealth applications and social media platforms in ways that empower one's sense of well-being and autonomy for defining what health and well-being means to them in a world filled with weight stigma.

I also have additional interests in health information-seeking behaviors and sexual health/experiences as mediated by technology, particularly as it pertains to Middle Eastern and North African (MENA) communities living in the U.S. Historically, there has been a limited amount of health-related research focusing on these communities, due to a variety of challenges such as recruitment challenges due to the community's lack of visibility in health records or official documentation.<sup>1</sup> A potential project I see stemming from this interest is centered on sexual health information-seeking behaviors for first-generation MENA Americans who may have unique experiences or challenges accessing or engaging with sexual health information due to factors like intracommunity stigma around sex<sup>2</sup>. This might include conducting interviews understanding attitudes around sexual health education and subsequent information-seeking behaviors and barriers to accessing sexual health information, followed with carrying out participatory design methods focused on improving sexual health education for this population. I would also be interested in understanding the experiences of MENA adults with online dating, sexual assault hotlines, etc. and how social stigma or stigma around sex shapes these experiences, particularly looking at adults along the axes of gender, sexual orientation, and age to understand intracommunity distinctions to better target sexual health information or digital health interventions. This project will lead to understanding how to improve accessibility for sexual health information to empower and protect community members to have autonomy and the know-how to manage their health and sexual experiences considering social stigma and stigma around sex. It will also contribute to learning how to best present sexual health information in ways that account for the specific values of the MENA community that have been historically excluded from many health-related research studies.

<sup>&</sup>lt;sup>1</sup> Abuelezam NN, El-Sayed AM and Galea S (2018) The Health of Arab Americans in the United States: An Updated Comprehensive Literature Review. Front. Public Health 6:262. doi: 10.3389/fpubh.2018.00262

<sup>&</sup>lt;sup>2</sup> https://www.arabamericannews.com/2018/03/16/local-public-health-effort-aims-to-de-stigmatize-sexual-health/

# **Potential Advisors**

While it is necessary to acquire and further develop the tools and skills to conduct interdisciplinary research aligned with UMSI's mission of social engagement information and computing, it is equally important to be advised by faculty that embody this mission with their research. Dr. Nazanin Andalibi, and Dr. Kentaro Toyama are two of the many<sup>3</sup> UMSI faculty that I would be interested in working with and learning from during my doctoral studies. Through my experience the last year and half being advised by Dr. Nazanin Andalibi, I know without a doubt that her research approach and interests in social computing that explores relationships between social media, self-disclosure of difficult and stigmatized experiences, and social support are directly related to my own fundamental interests. When reading Dr. Andalibi's publications about self-disclosure of miscarriages and seeking social support on social media as well as my experiences working with her directly, it is apparent to me that she has always centered people and their complexities in her work actively working to explore and find answers to questions that have the power to positively impact others. As this is something that I want to bring with me in my future career as a researcher and academic, I would love the opportunity to learn from and continue to be advised by someone who not only shares similar research interests, but also has a history of valuing human-centered research.

Another faculty member who I believe takes a human-centered approach with their research, as well as whose research expertise could help inform and support my research is Dr. Kentaro Toyama. Dr. Toyama's research repertoire covers a wide range of populations and geographic regions, as well as issues ranging from questions of information-seeking behaviors by African American mothers during pregnancy to digital literacy needs of the formerly incarcerated. With evidence of a breadth of experience researching digital technology for social change, as well as my personal experience of learning from Dr. Toyama in his role as Professor and thesis committee member, I am confident my

<sup>&</sup>lt;sup>3</sup> I also have interests of being advised by Dr. Mark Ackerman and learning from his expertise in healthrelated research with marginalized groups and information sharing. The only reason I have not delved into detail on Dr. Ackerman in this SOP is due to a note on his website that he is not recruiting students for the 2022-2023 year. However, if that were to change in the future as I proceed through the program, I would be interested in working with him.

work will be in good hands to have long-lasting impact. Also, I would be excited to see how Dr. Toyama's theory that technology amplifies human forces, whether positive or negative, may influence and shape my own work as I try to learn about phenomena and design that may amplify the good impacts and mitigate the negative that can occur with technology and humans.

It's important to me that the work I am involved in is human-centered and delivers findings grounded in real-world applications so that my research centered on improving the lives and lived experience of those facing stigma may be useful to as many who stand to benefit or intend to continue this line of research; from other researchers to health education professionals to social media designers to everyday people who want to preserve their sense of self- and well-being while engaging with technology. Dr. Andalibi and Dr. Toyama's affiliations with the Center for Ethics, Society, and Computing (ESC), and Dr. Andalibi's involvement with the Digital Studies Institute (DSI) at UM further motivate my wish to pursue my PhD at UMSI because of the additional opportunities to collaborate on projects in these organizations that align with my research goals. Being advised by those involved in human-centered research, such as Dr. Andalibi and/or Dr. Toyama, who have experience working with marginalized populations and those with stigmatized experiences, I know I will be in an advisor-advisee relationship that is mutually beneficial to our goals as researchers in social computing, HCI and health informatics.

Pursuing my PhD in Information Studies from UMSI would grant me the opportunity to continue engaging with the community I love at one of the top public universities in the world. UMSI brings students and faculty together from so many interdisciplinary backgrounds into its classrooms. Being able to remain a part of this diverse community and to continue to learn from those UMSI brings together, I feel confident I would be supported and learn the best practices to conduct research that can improve people's lives. I was once told that our imagination is the most powerful tool we have. Imagination leads to change. Change leads to action. Action leads to changes in our own realities. Our imagination, however, is of little use to us if we do not have a way to bring it to life. In pursuing a PhD from the School of Information, I will gain an incredibly powerful skill set and range of experiences that will bring my imagination into reality. I believe that every person, including those who have lived stigmatized experiences, fundamentally deserve to feel happy and safe in their own body. Technology and online social spaces can play a role in mediating kind, compassionate, and healthy relationships between the body and the self. I hope to identify the ways these technologies can be developed and designed during my doctoral study at UMSI.