.

Juan F. Maestre[+], Caroline Claisse[*], Angelika Strohmayer[x], Mark Warner[s], Abigail C. Durrant[*], Sarah Wydall[+], Deborah Jones[+] (2024): Conducting Interdisciplinary Research with Vulnerable Populations in Computing: Challenges, Practices, and Lessons Learned. In: Proceedings of the 22nd European Conference on Computer-Supported Cooperative Work: The International Venue on Practice-centered Computing on the Design of Cooperation Technologies - Workshop Proposals, Reports of the European Society for Socially Embedded Technologies (ISSN 2510-2591), DOI: 10.48340/ecscw2024_ws06

Conducting Interdisciplinary Research with Vulnerable Populations in Computing: Challenges, Practices, and Lessons Learned

Juan F. Maestre[+], Caroline Claisse[*], Angelika Strohmayer[x], Mark Warner[s], Abigail C. Durrant[*], Sarah Wydall[+], Deborah Jones[+]
[+]Swansea University, [*]Open Lab, Newcastle University, [x]Northumbria University, [s]University College London (UCL)
Contact author email: j.f.maestreavila@swansea.ac.uk

Abstract. The need for interdisciplinary approaches has become a necessity in Computer Science (CS) research. This is particularly the case with research involving the design and development of technologies that can have a significant impact on the wellbeing of people who are deemed potentially vulnerable (e.g., those living with stigmatized conditions or identities). However, in most cases, interdisciplinary research collaborations in CS fail to include experts from key areas whose knowledge and perspectives could benefit the end users and make the technology design process more ethical. In response, we propose a workshop bringing together

researchers and practitioners from CS, Design, and the Social and Health Sciences to discuss the challenges, practices, and lessons learned regarding such interdisciplinary research collaborations in the context of technology design with and for vulnerable groups. The outcomes of the workshop would provide insights on how to conduct this type of research more effectively and ethically.

1 Background and Motivation

Interdisciplinary research is a type of collaborative practice where experts from different disciplines co-produce knowledge based on the integration of methodologies from different domains (Sonnenwald, 2007; Jirotka et al., 2013). For example, Internet-based studies exploring social networks and online group contents have documented how and when interdisciplinary collaboration with experts from the Social Sciences, Arts and Humanities could take place. Research in online forums, in particular, has adapted ethnographic methods traditionally used in Sociology and the medical sciences to study user behavior and online communication (e.g., Bauermeister et al. (2019); Mo and Coulson (2013)). This type of *nethnographic* approach has required teams to work closely with research experts in ethnography and anthropology. The expertise brought from other domains has allowed researchers to plan studies and analyze collected data from human-centred perspectives. Their findings, in turn, have been translated into social policy via using methodologies that lie beyond the traditional training and expertise of computer science experts.

Yet, in spite of the advantages of having a plurality of perspectives and expertise from various domains in interdisciplinary research, there is still a lack of understanding of how to conduct effective interdisciplinary research in Computer Science such as in the case of the analysis, design, development, and implementation of digital technology (Blandford et al., 2018). For instance, Bonenfant and Meurs (2020) found that "social science researchers interested in mining [online] data often depend on data analysts who lack any social science background". Moreover, research involving digital technology design for vulnerable groups may fail to foresee and prevent unethical and negative consequences or impacts of technology introduction or implementation. This is particularly the case with algorithm-based technology which is often created, studied, tested, and deployed by experts and practitioners working in rather isolated domain circles composed by experts in artificial intelligence (AI) and machine learning (Bird et al., 2009). Consequently, technology design studies involving vulnerable populations (e.g., people living with chronic illnesses or living with a stigmatized condition such as being a prisoner or sex worker) may require additional work and overseeing by experts from legal and ethical-centered domains that could help make sure that the research agenda prioritizes the well-being, as well as the values, needs, and interests of the research-target

populations. For instance, Maestre et al. (2023, 2021) found that people living with the Human Immunodeficiency Virus (HIV) often felt further stigmatized when using digital interventions to improve medication adherence. The design of these interventions often employed stigmatizing language and imagery that made users feel as if they were being tracked to avoid the spreading of the virus (Maestre et al., 2023, 2021; Claisse et al., 2022).

Additionally, collaborations between Computer Science and Social Sciences tend to be "less structured, compartmentalized, and routinized, but more fluid, flexible, and open-ended" (Korn et al., 2017). Researchers from different domains may also work in different institutions located in different geographic locations (e.g., European researchers working with colleagues in regions or with population in the Global South). The lack of co-location with other researchers may complicate the carrying out of sensitive research tasks such as interacting with participants remotely, having access to and sharing sensitive digital data, etc. Thus, multi-disciplinary research may require much more careful planning of research goals and tasks, sharing of resources, as well as regarding the communication between members of a cooperative research team (Sonnenwald, 2007; Velden et al., 2014). A lack of appropriate planning and structure (physical and/or digital) in interdisciplinary research collaborations could cause misunderstandings and disruption in the achievement of common research goals, outcomes, and optimal ways in which new knowledge and outcomes should be disseminated and implemented across domains. Furthermore, such disruptions could involve other stakeholders as well such as study participants and members of gate keeping organizations and charities. In this sense, we argue that a discussion about the experiences and lessons learned in interdisciplinary technology design research endeavours is needed to further understand opportunities and challenges. There is still a lack of a guidelines on best practices that could provide recommendations on how to work with research colleagues in other disciplines in the context of technology design for vulnerable groups. Thus, we propose to organize a workshop that would gather a fairly diverse group of researchers and practitioners who have done technology design work with or for vulnerable groups. The outcome of the workshop will be the co-creation of materials (e.g., physical or virtual posters) as well as a post-workshop article or written piece on the workshop website that would summarize key insights derived from the workshop discussion and outputs.

2 Key Topics

The main topics to be covered in the workshop are as follows:

- **Finding research collaborators outside Computer Science:** This topic would focus on methods and best practices to search, identify, and invite researchers from other domains as well as community gatekeepers and voluntary organisations to a Computer Science research project. We plan to

emphasize participation of professionals and practitioners from core fields of the CSCW community involved in a socio-technical agenda (e.g., social work).

- **Collaborative research planning, design, and execution:** This topic would involve methods and best practices to improve communication of goals, planning and tasks among researchers from different fields during the entire study process.
- **Sharing of research outcomes across different disciplines:** This topic would cover the ways in which the outcomes of interdisciplinary research projects could be translated and used across different domains so that they are still valid and relevant to different audiences.
- **Ethical considerations:** This topic would cover the ethical underpinnings of interdisciplinary research involving digital technology design for vulnerable groups, and cultivating best practice and responsible design sensibilities.

3 Workshop Organizers (in alphabetical order)

Caroline (Caro) Claisse, PhD is a Lecturer in Human-Computer Interaction (HCI) and Interaction Design at Open Lab, Newcastle University. She is a designer by background inspired by Feminist, Social Justice and More-than-Human research. In her current work, she takes a design-led and co-creative approach to engage voluntary organisations and marginalised groups in research to inform the design of digital technologies and services that support personalised care and community wellbeing.

Abigail Durrant, PhD is a Professor of Interaction Design and Co-Director of Open Lab, Centre for Digital Citizens, and Northern Health Futures Hub at Newcastle University, predominantly working in the interdisciplinary and cross-sector field of HCI. Abi practices RtD using participatory and co-creative methods, for supporting dialogue, equitable engagement and digital inclusion. In her most recent collaborations, she critically engages with regional infrastructural programmes of digital transformation in health and care (e.g. about involvement in research on health data interactions).

Deborah Jones, PhD is a Professor in the Department of Criminology, Sociology, and Social Policy at Swansea University. Professor Jones is also the head of the School of Social Sciences. Throughout her research, she has focused on developing methodologies that are both inclusive and creative and has endeavoured to make academic research accessible to the community through a series of public education activities. In particular she has focused on the regulation of the sex industry co-leading The Student Sex Work Project. She has also explored how Higher Education can support desistance from offending.

Juan Fernando Maestre, PhD is a Lecturer (Assistant Professor) in the Department of Computer Science at Swansea University. His research applies novel participatory design methods to recruit and conduct research both in person

and remotely with vulnerable populations such as people living with stigmatized conditions and/or identities. He strives for a successful integration of novel research methods in order to design and assess the impact of technology-based interventions that support stigmatized, marginalized, and vulnerable populations.

Angelika Strohmayer, PhD is an Assistant Professor and co-leader of the Design Feminisms Research Group at Northumbria University's School of Design. She is an interdisciplinary researcher, working closely with third sector organisations and other stakeholders to co-design digital and craft-based interventions in service delivery and advocacy work. Her research lies at various intersections of practice-led and theoretical research surrounding issues of feminist and social justice-orientations.

Sarah Wydall is a Professor in the Department of Criminology, Sociology, and Social Policy at Swansea University. Their research interests focus on gendered harms, particularly on domestic abuse in later life. Since 2010, they have led on fifteen research projects, covering domestic abuse perpetrators, children and young people, victims labelled 'high risk' and more recently the intersection of later life, gender, disability and sexual identity. They have also co-produced and evaluated a Virtual Reality intervention 'Through their eyes as a training tool for the police and other service providers.

Mark Warner, PhD is a Lecturer (Assistant Professor) in the Department of Computer Science at UCL. He is an HCI researcher working at the intersection of privacy, security, and safety. Prior work includes research on sensitive disclosures within dating apps, drawing on user-centred research methods to engage with stigmatised users to better understand their lived experiences of disclosure within these apps. More recently, he has been involved in research analysing privacy mechanisms in FemTech apps and was involved in an interdisciplinary project exploring the use of data-driven systems to support the UK's response to the COVID-19 pandemic.

4 Workshop Outline

4.1 Prior to the Workshop: Website and Participants

- **Workshop website:** The organizers will create a website to share all the information about the workshop (e.g., dates, structure, activities, schedule) and call for participation with detailed instructions for preparing and submitting an expression of interest. The organizers will also disseminate the call for participation to the workshop via relevant email lists, professional and student networks, as well as via word of mouth.
- **Participants:** We will aim to recruit participants who are either PhD students, researchers, professionals, or practitioners who have worked in interdisciplinary research collaborations involving digital technology with and/or for vulnerable groups. Those interested in being part of the workshop will be required to fill out and submit their expression of interest to join the

workshop via an online application form. The form will confirm their expression of interest to be a workshop participant. It will also ask for an abstract of about 300 words where the potential participant will describe their research background and prior experiences in interdisciplinary research (e.g., lessons learned, challenges, etc.) We will also ask participants to share one image with a short caption that illustrate an aspect of their work with vulnerable populations, to symbolise a challenge, a snapshot of their practice etc. The form will also gather expectations from the workshop. We will select between 10-15 participants participants from different disciplines who work with a variety of populations, methods, and topics.

4.2 During the Workshop: Schedule, Format, and Materials

- **Schedule:** We propose a half-day workshop. As suggested in Table I, the workshop will last about 4 hours. In the first part, participants will be grouped in small groups with one co-organizer. Participants will give quick introductions to each other and the co-organizer will take notes and update a virtual board (i.e., Miro or Mural) containing the participants' profiles with key points about their research and past experiences. In the second part, participants will re-group again into small groups organized by the main topics described earlier in section 2. A workshop co-organizer will be leading the discussion in each group. During the small group sessions, each group will prepare a poster using markers and post-it notes (for those in person) or via using a virtual board (for those joining via Zoom) to capture key insights and conclusions. Finally, each group will present their poster to the rest of the workshop participants. We will close the workshop with conclusions and a brief discussion of directions for future work.

Duration	**Activity**
30 mins.	Welcome and introductions.
1 hour	Small group presentations and discussions on participants' experiences.
30 mins.	Coffee break and networking.
1 hour	Topic-based group sessions: discussion on highlight topics.
30 mins.	Group poster presentations.
15 mins.	Conclusions, impact & future work.

Table I. Workshop Schedule.

- **Format:** This will be a hybrid workshop. Participants will be able to join the workshop either in person or via Zoom in order to maximize opportunities for participation. At least two co-organizers will be present in person during the

entire duration of the workshop. The rest would participate remotely leading and moderating the workshop activities. Online participants will be projected using a projector screen located in the workshop room, or via a laptop in each discussion group. Careful consideration will be given to turn-taking and balancing contributions from those participating online and in-person.

- **Materials and equipment:** We will request the conference organizers to provide us with a projector and a big screen (for the projector) as well as wireless Internet connectivity. The workshop co-organizers and online participants will be asked to use their own computers or laptops to present and/or participate.

4.3 After the Workshop

Notes taken by the workshop organizers and resulting posters from the group sessions will be used to facilitate the writing of an article submission for publication. This article will reflect upon the main outputs and insights from the workshop and will be collaboratively produced by workshop organizers and interested participants.

References

Bauermeister, J., K. Muessig, S. LeGrand, D. Flores, S. Choi, W. Dong, G. Sallabank, and L. Hightow-Weidman (2019): 'HIV and sexuality stigma reduction through engagement in online forums: results from the HealthMPowerment intervention'. *AIDS and behavior*, vol. 23, no. 3, pp. 742–752.

Bird, C., P. Devanbu, E. Barr, V. Filkov, A. Nash, and Z. Su (2009): *Structure and Dynamics of Research Collaboration in Computer Science*, pp. 826–837.

Blandford, A., J. Gibbs, N. Newhouse, O. Perski, A. Singh, and E. Murray (2018): 'Seven lessons for interdisciplinary research on interactive digital health interventions'. *DIGITAL HEALTH*, vol. 4, pp. 2055207618770325. PMID: 29942629.

Bonenfant, M. and M.-J. Meurs (2020): *Collaboration Between Social Sciences and Computer Science: Toward a Cross-Disciplinary Methodology for Studying Big Social Data from Online Communities*, pp. 47–63. Dordrecht: Springer Netherlands.

Claisse, C., B. Kasadha, S. Stumpf, and A. C. Durrant (2022): 'Investigating daily practices of self-care to inform the design of supportive health technologies for living and ageing well with HIV'. In: *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems*. pp. 1–19.

Jirotka, M., C. P. Lee, and G. M. Olson (2013): 'Supporting scientific collaboration: Methods, tools and concepts'. *Computer Supported Cooperative Work (CSCW)*, vol. 22, pp. 667–715.

Korn, M., M. Schorch, V. Pipek, M. Bietz, C. Østerlund, R. Procter, D. Ribes, and R. Williams (2017): 'E-Infrastructures for Research Collaboration: The Case of the Social Sciences and Humanities'. In: *Companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*. New York, NY, USA, p. 415–420, Association for Computing Machinery.

Maestre, J. F., D. V. Groves, M. Furness, and P. C. Shih (2023): '" It's like With the Pregnancy Tests": Co-design of Speculative Technology for Public HIV-related Stigma and its Implications for Social Media'. In: *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems*. pp. 1–21.

Maestre, J. F., P. Zdziarska, A. Min, A. N. Baglione, C.-F. Chung, and P. C. Shih (2021): 'Not another medication adherence app: Critical reflections on addressing public HIV-related stigma through design'. *Proceedings of the ACM on Human-Computer Interaction*, vol. 4, no. CSCW3, pp. 1–28.

Mo, P. K. and N. S. Coulson (2013): 'Online support group use and psychological health for individuals living with HIV/AIDS'. *Patient Education and Counseling*, vol. 93, no. 3, pp. 426–432.

Sonnenwald, D. H. (2007): 'Scientific collaboration'. *Annu. Rev. Inf. Sci. Technol.*, vol. 41, no. 1, pp. 643–681.

Velden, T., M. J. Bietz, E. I. Diamant, J. D. Herbsleb, J. Howison, D. Ribes, and S. B. Steinhardt (2014): 'Sharing, re-use and circulation of resources in cooperative scientific work'. In: *Proceedings of the Companion Publication of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing*. New York, NY, USA, p. 347–350, Association for Computing Machinery.