

Program: Data Donation Symposium

Day 1 – Thursday, 30 May 2024

Time	Activity	Presenter
12:00-12:45	<i>Walk-in and registrations</i>	
12:45	Opening	
12:55	<p>Keynote</p> <p>Data4Science: Agency, Transparency and Reciprocity in Data Donation</p> <p>Individuals are increasingly aware of the large amounts of personal data collected from them by when they use services and want more agency in the use and understanding of their own personal data. At the same time, this valuable personal data that could generate fundamental discoveries to benefit the public good is often inaccessible for scientific researchers. They lack agency, transparency and reciprocity. Leveraging recent GDPR regulations of the right to data portability, Data4Science (D4S) is a trusted platform for individuals to take control of their own data, donate, understand it, shape their own behaviour and share it for broader health and behavioural research. Donated data includes data from social media, professional sites, wearables, internet searches and watches, mobility, genetics to microbiome and beyond.</p>	<i>Melinda Mills</i>
13:55	<i>Coffee Break</i>	
14:15	Session: Challenges on Participant Engagement	
	<p>Increasing Data Donation Compliance: Exploring New Strategies and Characteristics Why Do People Self-Select Out of Data Donation Studies? Cross-National Insights from Germany and the Netherlands Towards Co-Created and Collaborative Data Donation Projects Recruiting Data Donors through Social Media Advertisements – Opportunities and Caveats Once in a lifetime - Pros and cons of a full-scale DDP approach</p>	<p><i>Ernesto de León</i></p> <p><i>Valerie Hase</i></p> <p><i>Alejandra Gomez Ortega</i></p> <p><i>Thomas Friemel</i></p> <p><i>Zoltán Kmetty</i></p>
15:15	A demonstration of the data donation software <i>Port</i>	<i>Niek de Schipper</i>
15:30	<i>Coffee Break</i>	
16:00	High-Density Session: Study Designs	
	<p>A feasibility pilot of data donation among a nationally representative panel of survey respondents Negotiated consent for data donation in clinical research Mapping online exposure to gambling marketing communication for vulnerable groups: a data donation study</p>	<p><i>Sherry Emery</i></p> <p><i>Zahra Ghasia</i></p> <p><i>Lauranna Teunissen</i></p>

	Measuring the effect of a seven-day Instagram abstinence on users' body image by combining survey and donated data	<i>Daria Szafran</i>
	Investigating Rabbit Holes in Social Media Usage: A Novel Perspective Using Data Donation	<i>Qiru Huo</i>
	Two become one: A collaborative data donation project using Netflix viewing data	<i>Joël Hendrix & Gijssje Maas</i>
	Ethical Considerations in Exploring Student Interactions with ChatGPT: A Pilot Study in the Netherlands	<i>Karin van Es</i>
	Unlocking Insights into Adolescent Peer Relationships Through Social Media Data Donations	<i>Loes Pouwels</i>
	Exploring Well-being in Gender and Sexual Minorities: Understanding the Buffering Role of Online Community	<i>Charlie Loopuijt</i>
<i>17:00-18:00</i>	<i>Drinks</i>	

Day 2 – Friday, 31 May 2024

Time	Activity	Presenter
9:00	Session: Data Donation Infrastructures	
	The RegretsReporter Program: evolving methods to meet research challenges with crowdsourced data	<i>Jesse McCrosky</i>
	Bridging the Gap: Using Data Donations to Enhance Adolescent Cohort studies	<i>Sebastian Kurten</i>
	Augmenting data donations – integrating TikTok DDPs, video metadata, and the multimodal nature of audio-visual content	<i>Lion Wedel</i>
	Port data donation software service on the Next platform	<i>Adrienne Mendrik</i>
	Hate Speech and Misinformation on WhatsApp: Insights from a Large Data Donation Program in India and Brazil	<i>Simon Chauchard</i>
<i>10:00</i>	<i>Coffee Break</i>	
10:30	Session: Applications in Health and Physical Activity	
	Measurement of Physical Activity in Older Adults through Data Donation	<i>Bella Struminskaya</i>
	Urban Hearing: Investigating individual noise, stress, sleep, and smartphone use via Apple Watch and iPhone Data Donation	<i>Paulien Decorte</i>
	Mapping digital food environment on social media: a data donation approach	<i>Kaiyang Qin</i>
	Tesco Data Portability Tool: Empowering customers to donate shopping data for chronic pain research	<i>Neo Poon</i>
	Data donation of personal physical activity trackers	<i>Maaike Kompier</i>
<i>11:30</i>	<i>Coffee Break</i>	
11:45	Session: Evaluation of Data Donation Approaches	
	A Systematic Review of Data Donation Literature: Defining Key Concepts, Best Practices, and Directions for Future Research	<i>Yucan Xiong</i>

	<p>Private messaging not so private: Is donating WhatsApp chats a good idea?</p> <p>Data Donations in the Media: The public portrayal of a promising method</p> <p>Understanding the Potential of Data Donations: Evaluating Platform Compliance for Impactful Insights</p>	<p><i>Felicia Loecherbach</i></p> <p><i>Elisabeth Schmidbauer</i></p> <p><i>Leonie Manzke</i></p>
<i>12:35</i>	<i>Lunch</i>	
13:35	Session: Challenges Related to Legal, Ethical Considerations or Platform Restrictions	
	<p>How digital platforms may narrow down data access rights: data download packages reveal platform interpretations of GDPR obligations</p> <p>Yet Another Privacy Paradox? Stated intention and actual willingness for data donations</p> <p>Development of a TikTok Data Donation Study Among Adolescents: A Promising Method, A Challenging Process</p> <p>Measuring Privacy Behavior with Donated Data</p> <p>The Feasibility of WhatsApp Chat Log Donations: Willingness vs. actual Donations in an opt-in Sample.</p>	<p><i>Heleen Janssen</i></p> <p><i>Philipp Hartl</i></p> <p><i>Nadia bij de Vaate</i></p> <p><i>Frieder Rodewald, Florian Keusch</i></p> <p><i>Julian Kohne</i></p>
<i>14:35</i>	<i>Coffee Break</i>	
15:05	Session: Data Donation Applications	
	<p>Investigating the influence of friendships on YouTube usage history similarity using data donations</p> <p>Subjective and objective perceptions of hate speech in Switzerland</p> <p>Enhancing Social Media Data Donation for Research: A Researcher-Assisted Approach</p> <p>Data donations: A mixed-methods approach to explore how users engage with news</p> <p>Analyzing User Engagement with TikTok's Short Format Video Recommendations using Data Donations</p> <p>Behind the Screens: Exploring Netflix via Data Donations</p>	<p><i>Nico Pfiffner</i></p> <p><i>Dominique Wirz</i></p> <p><i>Yibei Yu, Xiaohua He</i></p> <p><i>Tim Groot Kormelink</i></p> <p><i>Savvas Zannettou</i></p> <p><i>Dennis Nguyen</i></p>
<i>16:20-16:30</i>	<i>Closing</i>	