

SODA is an EU funded research collaboration of universities and industries across Europe exploring the potential of using multiparty computing (MPC) in the health domain.

SODA@Lancaster University is contributing by exploring perceived benefits and fears about data sharing, together with people living with dementia and their caregivers.

NeuroDropIn
Together better

SODA@Lancaster project partnered with the Neurodropin Center in Lancaster and their support group, that usually meets every Tuesday for a social lunch.



Research through collaborative creative activities



Workshop activities integrate making and storytelling, music and cartoons, to catalyse participatory research on issues of medical and personal data sharing, such as privacy, trust and justice.

Soda Explored issues of consent using cartoons



Ethical Approval Forms and Project Information Sheets were 'translated' into a visual media, using comic strip format, creating something more accessible, easier to see and understand, key for the initial relation with participants.

Participants co-created data subjects



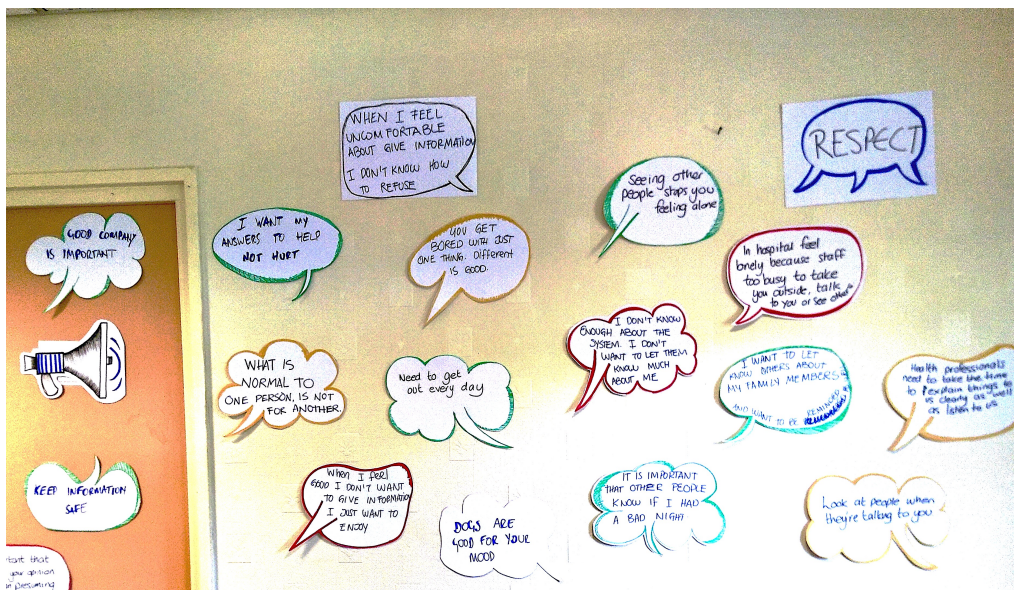
Inspired by participatory storytelling, participants created in collaboration their idea of data subjects, what objects, stories, numbers and things would matter to them.

Building Scenarios



Participants placed the data subject and their stories in scenarios, mobilising data personas into an interconnected datafied context. Relating everyday activities with data generation, data sharing and data purpose.

Reflective conversations



Soda sessions aimed to engage participants as experts rather than patients. Their voices were recorded visually on the wall. This dynamic was inspiring for participants who expressed pride and fulfilment at their voices being taken seriously.

Cultural Probes - Caregivers



During the month of activities participating caregivers kept a diary, a voice recorder and a camera, to record everyday experiences of sharing personal and medical data on behalf of people living with dementia.

What is Next?

The project is looking at issues of perceptions of data sharing from two angles; data subjects, or, people living with dementia, and, system end users, or, people whose job it is to do data analytics or that operate medical data.

SODA@Lancaster University is designing forthcoming workshops with end users as the next research activities.

The findings of all groups will be included in guidance for designing and operating collaborative data management systems.



The design of all research activities by **SODA@Lancaster** were informed by an explorative workshop with both groups run in Nov'17. For more about past and future events, visit: http://imagination.lancs.ac.uk/activities/SODA_Project_1

SODA@Lancaster creative activities were designed and delivered in collaboration with Jacqueline Harris, storyteller; Paris Selinas, cartoonist; Dr. Luke Moffat, Philosopher and Jess Robins, Documenting.

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