
POSTER ABSTRACT

We Are: Giving citizens control over their data.

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Summary: The We Are platform gives citizens control of their own health data and actively involves them in decisions about the platform that manages the data, thereby guaranteeing them that they can manage and share their data in a safe way as a leverage for personal wellbeing and the common good.

Challenge: Data about citizens, consumers and patients is collected by the government in order to make policies, by companies to develop new products and for marketing and sales, or by hospitals, universities and knowledge institutions for research and innovation. Smart use of data is leading to new insights, valuable innovative processes and even better medicines and health care. Big data will allow us to have a better understanding of who is at risk from specific diseases and who benefits from particular treatments.

This can only happen if the data does not continue to be gathered and stored in separate silos. Bringing together data from a wide variety of sources creates inconceivable opportunities for research and development, but it will also require the data to be handled with extreme care.

Engaging citizens and technology to do something about it: To this end, a Flemish consortium is building a platform providing a personal digital data safe, based for each Flemish citizen. The SOLID technology, a new way of managing data on the web, provides citizens with their own data safe in which they can store their personal data. Citizens manage this safe themselves. They only must enter their data once and can then immediately reuse it for the applications they prefer.

All safes are maintained together by a legal entity like a cooperative society. The cooperative governance structure is socially engaged and, on behalf of citizens, ensures utilisation of personal data for innovations aimed at a sustainable health system.

What are the next steps, what is the impact: Hence, the combination of personal health data types of all citizens, ranging from lifestyle to wellbeing, curated by themselves, is an unprecedented resource for sustainable innovation & growth, provided the access is arranged, by design, in an ethical way and compliant with legislation. It provides a way to enrich personal health data in a natural way and to collect citizen generated data which is currently often lost or scattered.

The realisation of this system innovation requires various activities in which all possible stakeholders (government, companies, research community, civil society and citizens, cf. the

quadruple helix) have an important role to play. Doing so, we believe citizen-centered data management will contribute to the empowerment of the patient as a pilot in integrated care