

Informatie ICT.OPEN2019

Track theme: "making data work for health"

In close consultation with the health care and research field, Dutch Minister for Healthcare and Sports Bruno Bruins has developed a vision how data can be employed to serve health. He has shared this vision in a letter to the Dutch Parliament (15 November 2018), entitled 'Data laten werken voor gezondheid'. This letter has led to COMMIT/ and DTL organising this track.

Some quotes derived from this letter to the Parliament (roughly translated from Dutch):

'To make data work for health, trust is needed. A patient should be able to rely on his/her data being handled with care, and a healthcare provider should be able to rely on the validity of the results from data analyses. Data should be stored safely, but information should flow if necessary or desirable.'

An important method of analysis is the Personal Health Train (PHT). 'The most important concept of the Personal Health Train (PHT) is that the data is not brought to the analysis, but the analysis is brought to the data. The data remain at the source (in line with the outcome targets of the Health Information Council) and it offers the possibility to apply complex (self-learning) algorithms at the source...'

'A wide implementation of the PHT requires further research and coordination. For example, questions regarding technology, privacy and organizational aspects that should be addressed first.' [Source: Appendix to the letter to Parliament '[Praktijktoets FAIR data & Personal Health Train](#)']

Aim of the track

In line with this theme, a series of challenges have been formulated. In this track, DTL and COMMIT/ aim to work with expert representatives of the Life Sciences and Computer Science communities towards solving these challenges, and to work towards a collective research and innovation agenda on the PHT approach. The outcome of the track will be shared with the Minister and will be used to build a coalition of parties that can help realise this agenda.

Further information

In one of the annexes to the Parliament 'Hoe kunnen we zorggegevens beter toegankelijk maken', the PHT concept is further explained. Also, a simulation has been performed of the PHT visiting data stations of healthcare providers. The Minister concludes that the PHT has the potential (in the care sector) to assist in automating information gathering, that it offers the possibility to tune information to individual patients and that it can help safeguard the privacy of patients.

The Minister has also formulated a number of challenges, such as around aspects of logging, auditing and transparency of analyses, implementation of the General Data Protection Regulation (GDPR) and other privacy-related aspects. At a technical/scientific level there is also a challenge how this distributed approach can serve to answer questions without gathering information in a central place. How can we push the boundaries to allow working with distributed and heterogeneous datasets? These challenges will be addressed in the track.

Background information

- Link to Letter to the Parliament "data laten werken voor gezondheid" plus annexes (in Dutch): www.rijksoverheid.nl/documenten/kamerstukken/2018/11/15/kamerbrief-over-data-laten-werken-voor-gezondheid
- Link to the Personal Health Train animation <https://vimeo.com/143245835>

Waiver

Thanks to COMMIT sponsoring all track participants will receive a conference fee waiver for the full 2-day ICT.OPEN2019 conference (€ 145,20 p.p). The conference fee waiver includes for 2 days: coffee breaks, lunches, drinks and dinner on 19 March 2019. Accommodation is not included.

Special registration

In order to facilitate diverse constructive discussions, the total number of participants to the sessions on *distributed learning on personal data* will be limited to about 20.

If you did not receive an invitation to the track and wish to participate, please send an email **with a brief (5 lines) motivation of your wish to participate and the benefit of your participation to the track** to m.vanduin@nwo.nl, **15 February** at the latest. Please keep in mind that a selection will take place and you may not be selected to attend the sessions. You will receive a decision concerning your attendance by 21 February.

COMMIT

In the coming years, COMMIT/ will undertake various activities to strengthen, link and make visible the public-private partnership in the field of ICT Science. For six years knowledge institutions (general and technical universities), start-ups, SMEs, corporate companies and non-profit organisations across the entire ICT-Science worked together in the COMMIT/ ICT research program. More than 130 partners worked together in this public-private partnership until 2017. From security to e-health and from human-machine interaction to e-food.

DTL

DTL, the Dutch Techcentre for Life sciences builds a public-private network of experts dealing with the growing challenges in the life sciences. Meanwhile, over 50 partners in the DTL network are actively engaged in agenda-building in data analytics, data stewardship and related data infrastructure. In the health sector, DTL strongly supports the development of Health-RI as the national infrastructure for Health research.