



Co-production of knowledge

Vision and Aims

Huntington's disease (HD) is a rare, hereditary, incurable, "neurodegenerative" genetic disease that causes significant motor, cognitive and psychiatric disorders and usually develops in mid-life. Incurable, but detectable by genetic testing. What happens when medical science knows how to detect but has no therapy to offer? Dingdingdong's answer comes from the sciences, the arts, without forgetting the people concerned.

Initiated in France and Belgium in 2012, Dingdingdong aims to build knowledge about Huntington's disease that is co-produced with concerned people. By concerned people we mean not only directly affected persons, but also affected families, caretakers, doctors, physicians... Dingdingdong was born to take the measure of a very particular problem - how to live well with a disease such as Huntington's? - which currently puts all these people in great difficulty. By bringing together historians, philosophers, psychologists, neurologists, dancers, filmmakers, visual artists, and writers, we have taken up the challenge of creating relevant knowledge, i.e., knowledge that is effective in relation to HD with and for its users, and, at the same time, of putting our practices into the school, or more precisely, into the anti-school, of HD. Along the way, Dingdingdong hopes to create new ways of understanding an experience that potentially concerns us all: living with a genetically predicted disease.

The Dingdingdong collective frees itself completely from the current asymmetries between scientific and profane knowledge, between scientific and artistic practices. It is really a question of putting our practices to the test, that is to say of taking the measure of the effects they produce in an interaction assumed with the various stakeholders to whom they are addressed. The arts and sciences, despite their desire to transform society, find it very difficult to move beyond issues internal to their own disciplines and to think the impact of their work not only in terms of diffusion. It is very difficult to think of arts and sciences in a situated way, not in the sense of denunciation or sensitization, in other words of a knowledge in a unique sense, but in the sense of co-production of an acting knowledge. Dingdingdong poses as an institution, but in our case to make fragile knowledge and deploy alternative ways of doing art and research, contrary to what the term institute usually covers. We do not seek to remain neutral, to produce evidence, to avoid at all costs the methodological biases characteristic of scientific objectivity, or to seek the unprecedented, to place the focus on the "artist", characteristic of the art worlds. On the other hand, we commit ourselves to give a very scrupulous account of the way in which our attachments, our hesitations, our uncertainties, symmetrically with those of our interlocutors, can contribute to co-produce knowledge. We do not seek to "make science" but to "make knowledge".

27-30
April 2021

RESEARCH & INNOVATION

EU Knowledge Valorisation WEEK

#EURResearchArea

#valorisation

Target Audience	Carriers, patients, relatives, doctors, caregivers, scientists, artists, health professionals, public authorities.
Key Features	<ul style="list-style-type: none">• Plurality of knowledge : producing experiential knowledge does not mean substituting a more subjective definition for the medical definition, but rather of allowing several versions of HD to coexist. Our mission is to take care of the multiple experiences of HD, from the point of view of those affected (patients, carriers, relatives) as well as from that of the caregivers and doctors, and to create a form of knowledge that has a voice, with which all the characters in this story must form an alliance.• Coproduction of knowledge : to create ways of making knowledge with the users, and not behind their backs, to deploy all the tact necessary for such a delicate task so as never to crush the absolute singularity of each experience; on the other hand, to "make knowledge", especially in the sense of accompanying our work in the world so that it becomes effective, meaning « translating » our results into different forms of dissemination, each form has to be thought in a way that can reach a specific community : scientists (posters), families and caregivers (film), etc, and to be accompanied (follow the effects).• Impact of knowledge : following pragmatist philosophy, a concept, an idea or a creation is not evaluated a priori and in abstraction from concrete situations. On the contrary, their epistemological value depends only on their real effects, on the differences they are able to produce in the world. In other words, their "cash-value" is found in the experience of those they concern and we must learn to follow the effects of knowledge. <p>Among others....</p>
Launch Date	Started in 2012
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