Briefing HARMONY explanatory animated videos number 1, 2 and 3

To: whom it may concern **HARMONY Partners, Patient Cluster, Associated Members**	Date: 05 07 2019
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1. Objective of the HARMONY explanatory animated videos:

Big data is an abstract term. Big data in health and in particular in blood cancer c.q. hematology is even more difficult to grasp. HARMONY created 3 videos for a broader audience (general public). In a short animated manner, we explain what HARMONY is, its reason for being and how to understand what making use of big data analytics could mean to blood cancer patients. In addition, we zoom in on how data quality, safety, and privacy is are secured.

> **We encourage you to share these animations on your digital and social media platforms to help reaching the right audience and to increase awareness of HARMONY. We have developed a number of tweets, which you can adapt and translate.**

2. Where to find the HARMONY explanatory animated videos:

2.1 On the HARMONY website: https://www.harmony-alliance.eu/en/news/wp7/3-new-harmony-video-animations-explaining-big-data-in-hematology

2.2 Or on the HARMONY YouTube Channel:
- Video 1: https://youtu.be/qEYauSGiDJo
- Video 2: https://youtu.be/cbbi5V_4T7w
- Video 3: https://youtu.be/wJQaw5cn4CU

2.3 The 3 videos are also available with subtitles in English. You will find them on the HARMONY Community Forum in the WP7 Archives Group (including the cover images):
https://internal.harmony-alliance.eu/post/518

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3. Sharing the explanatory animated videos through social media:

3.1 An overview of our accounts:
- Twitter: @HARMONYNetEU
- LinkedIN: Harmony Alliance | European Network of Excellence for Big Data in Hematology
- Facebook (not very active): HARMONY Alliance

3.2 Requested hashtag: #bigdataforbloodcancer

3.3 Suggested tweets:

Video 1: HARMONY Alliance: BigData & Blood Cancer, an introduction
- The Harmony Alliance is the first-of-its-kind public-private partnership to seek to enable better, faster treatments for patients with #bloodcancers #hematological malignancies #bigdataforbloodcancer #hematology
- Check out how @HARMONYNetEU is leading the way to #bigdata analytics in #hematology #bigdataforbloodcancer #bloodcancers

Video 2: HARMONY Alliance: Why big data
- Why do we need big data in #bloodcancer research? #bigdataforbloodcancer #hematology
- When it comes to #bigdataforbloodcancer every patient counts for personalized medicine #hematology #bloodcancers

Video 3: HARMONY Alliance: Ethics, data quality, safety and privacy
- The HARMONY Alliance data-handling procedures ensures maximum protection of #patients' privacy #bigdataforbloodcancer #bloodcancers #hematology
- Responsibility towards ethics and privacy, check how the HARMONY Alliance set this up #bigdataforbloodcancer #bloodcancers #hematology

3.4 Suggested (cover) images:

Find them here: https://internal.harmony-alliance.eu/post/518

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3. Text of the videos

Video 1: BigData & blood cancers: what and why?

Blood cancers include diseases such as leukemia, lymphoma and myeloma, all of which have an impact on the production and function of blood cells. Developing and optimizing treatments for these life-threatening diseases – many of them rare – can be a complicated process. Collecting and harmonizing high-quality data on outcomes of existing treatments is crucial but often hampered by lack of data as well as variations in healthcare practice throughout Europe, presenting a challenge to clinicians, researchers and regulators.
The HARMONY Alliance is a European Network of Excellence consisting of over 80 public-private organizations. At HARMONY, we are working together to collect data from all over Europe on as many patients with blood cancers as possible. We anonymize these data and assemble them in one harmonized Big Data Platform. By building the HARMONY Big Data Platform, we can undertake Big Data analysis, improving our understanding of these rare conditions, and shortening the process for the development of new drugs or treatment approaches.

Video 2: Why do we need Big Data?

The HARMONY Alliance uses Big Data to improve care for patients with blood cancers such as leukemia, lymphoma, and myeloma. We aim to develop treatments that are more effective, have fewer side effects, and secure a higher quality of life. However, the best possible treatment may differ from one person to another. This is partly due to biological differences, such as the genetic characteristics of the tumor cells. If we could predict the course of a disease and how it responds to treatment on the basis of biological factors, we could offer patients a tailored treatment. This is called "personalized medicine".
Spread all across Europe, databases from clinical studies and public registries contain clinical and biological data from thousands of blood cancer patients. We anonymize these data records and assemble them into one harmonized Big Data Platform. HARMONY researchers can use this platform to answer a variety of research questions and learn how to predict the development of a particular disease and how certain subgroups of patients will respond to treatment. Ultimately, this should result in tools that will enable clinicians and doctors to rapidly select the most promising treatment for a particular patient. Reliable predictions require data from thousands of patients. Hence, every patient counts, and HARMONY is actively working to involve an increasing number of European medical centers in the Alliance community.

Video 3: How does HARMONY ensure data quality, safety, and privacy?

The HARMONY Alliance has created a Big Data Platform to improve the treatment of blood cancers. Our data-handling procedures ensure that we provide maximum protection of the patients' privacy, while leaving the data rich enough for meaningful scientific analysis. This works as follows: Several boxes must be ticked before a data record may enter the HARMONY data platform. The data is:

− carefully checked for completeness and correctness;
− harmonized, meaning that it is given the same format as the other data contained in HARMONY's Big Data Platform; and
− edited, so that it would require an unreasonable amount of effort to identify the patient who is the source of the data. This is called "de-facto anonymization", and is a process that complies with ethical guidelines and European data protection laws.

Once the anonymized data record is in the HARMONY Big Data Platform, it is protected from unauthorized access through technical and organizational measures. For instance, a researcher will only get access to those data elements that are essential to answer his or her specific research question. Taken together, these measures ensure high quality and secure data that will help us improve the treatment of blood cancers.