



MultipleMS Newsletter #2 – August 2017

During the projects first 6 months, main focus of *MultipleMS* has been to submit all the approvals and legal forms to the EU (described below) while preparing to start up with collecting data from our MS patients.

An extensive amount of work has been done for completing the ***MultipleMS* Data Transfer Agreement (DTA)**. This plan ensures that the privacy of the patients enrolled in the project is warranted and provides general guidelines regarding publication strategy of results from existing project data, how to structure information from published studies (i.e. information that is already in the public domain – summary statistics and individual level data), unpublished local studies contributed by individual parties and data generated as part of *MultipleMS*. The Institute for Molecular Medicine Finland (FIMM) and Karolinska Institutet (Sweden) are working on solving the remaining issues regarding the DTA, foremost concerning the new General Data Protection Regulation legislation announced by the EU.

Ethical permits and informed consent forms from all the participating centres on existing data have been sent to EU.

The **standard operating procedure (SOP)** for collection of biomaterial sampling from our prospective MS cohort is now ready. The procedure includes longitudinal collection of whole blood, isolation of peripheral mononuclear cells, DNA, RNA, Serum and Plasma from newly diagnosed MS patients at the time of inclusion. The individual centres are currently testing this SOP and will send their test samples to the Technical University of Munich (Germany) for quality control. Recruiting the first prospective MS patients is due within the next months.

For the **common database**, the example files of data each centres' data structure have been sent to FIMM, along with a map that explains each data entries origin (for example how the data of birth is annotated and recorded). With these examples, FIMM has now configured their software to harmonise all entries. As soon as the DTA is in place each centre can transfer data for their existing cohorts.

The ***MultipleMS* Communication, Dissemination and Exploitation (CDE) – plan** was submitted to the EU 21st of June, 2017. The plan describe the communication tools for internal- and external communication, the strategy and activities to promote both the project and its results, and how to inform all stakeholders (often in a two-way interaction

mode), how we will make results available to the general public for further use, and the actual use of results (knowledge, methods, agreements, networks and technologies).

Some of the action points from the CDE-plan are already accomplished (and will continuously be updated as the project proceeds:

- An official *MultipleMS* **Facebook page; MultipleMS EU Horizon2020** (Figure 1a). Recently, “why”-statements from some of our executive board leader has been published on our Facebook page. New statements will regularly be published during the next months.
- The *MultipleMS* **webpage** (<http://www.multiplems.eu>).
- **Twitter account (@MultipleMS_EU)** (Figure 1b).
- The *MultipleMS* **information leaflets** are soon ready.

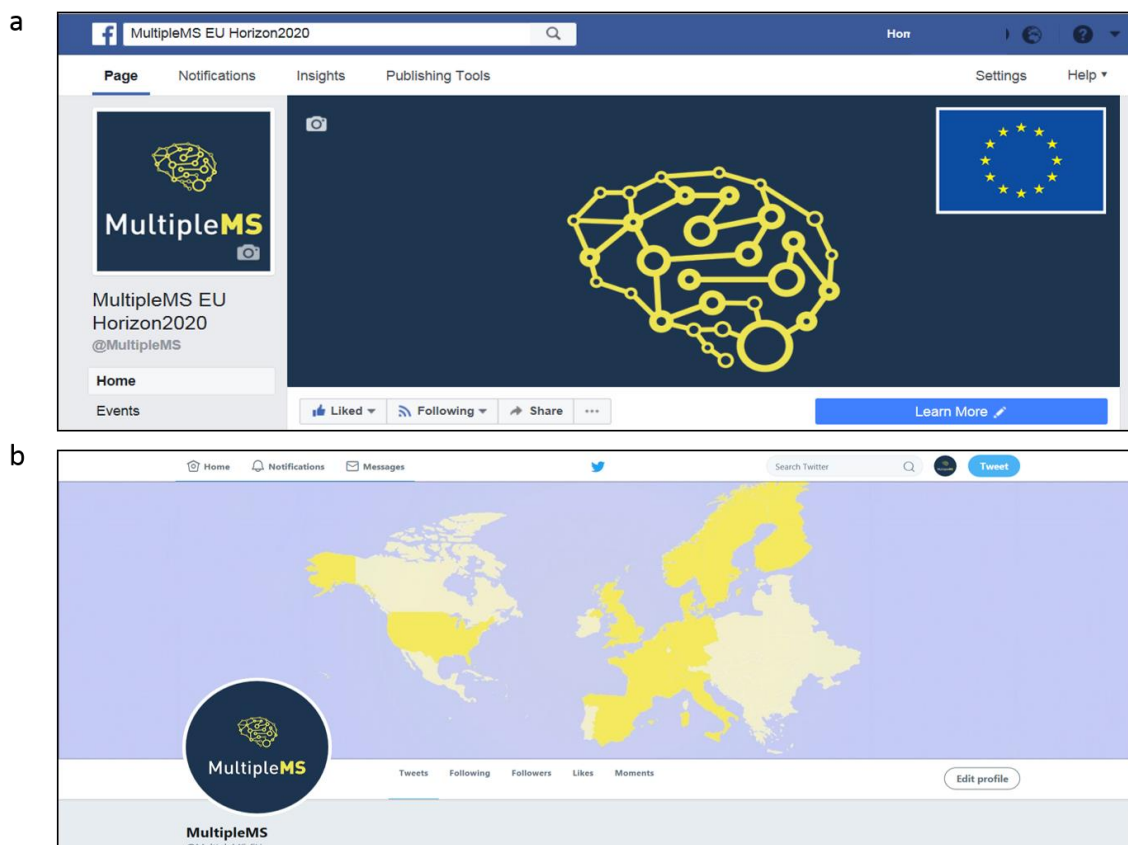


Figure 1: Screenshot of the official *MultipleMS* Facebook page (a) and Twitter account (b).

Upcoming events:

- ***MultipleMS* face-to-face meeting in Paris**, October 23rd-24th: The first part of the *MultipleMS* meeting takes place at the Paris-CDG airport on the afternoon of Monday 23rd of October. The next morning on October 24th the meeting continues close to the ECTRIMS conference site. After the lunch, the IMSGC will meet at the same location.
- **PhD Challenge**: November 2017 (Copenhagen, Denmark).
- **MultipleMS annual meeting and ‘stakeholder workshop’**: May 2018 (Cambridge, UK).