

BFCC Requirement Workshop Denmark

Minutes

Date/Time	14th June 2018, 11:00-12:30
Venue	J. B. Winsløws Vej 19, room 1901 (ground floor), Odense University Hospital, 5000 Odense C, Denmark
Host	ScanBalt
Scope	Input from Stakeholders to BFCC in general and to the register in particular
Minutes	Imke Schneemann, Life Science Nord

Agenda

Time	Topic	Responsible
11.00	Welcome by BONEBANK	Arndt Peter Schulz, Universitätsklinikum Schleswig-Holstein
11.05	Introduction to BFCC	Imke Schneemann, Life Science Nord
11.20	Round Table: Stakeholder requirements	Imke Schneemann, Life Science Nord
12.20	Conclusions	Ralf Duckert, DSN Connection Knowledge
12.30	Light lunch	

A general introduction to the BFCC project was given by Imke Schneemann. Arndt Peter Schulz talked about the BFCC registry in its current status in more detail afterwards. Thereby all pilot actions were mentioned and the relation to the transnational registry was demonstrated. The dataset and especially the common minimal dataset were shown (https://www.bfcc-project.eu/files/MinimalDataSet/bfcc_dd_browser.html).



Questions aroused regarding the process of data entry and the content of the informed consent. What is included in the informed consent regarding data, data ownership and usage? At the moment, the informed consent concentrates on research regarding the performance of the registry. Upon request, the function of the trusted third party were described in more detail as well as the data ownership: Each hospital owns its own data and has fully access to their own data so far. The complication pilot has been described in more detail by Arndt-Peter Schulz (UKSH).

It was of interest how the collaboration with the existing fracture registry in Sweden works and it was mentioned that integration of a high amount of data to an existing registry would be an enormous benefit for the BFCC registry. Moreover, it became clear that a lot of man power is needed to run a registry. The Danish fracture registry is financed by the government and thus, the government owns the registry itself. Patient data automatically go into the registry. Only if research is planned the patient has to be asked for his/her consent. However, there might be reservations towards collaboration of the Danish national registry with industry. Nevertheless, Odense University Hospital might be interested to join the BFCC in a potential extension stage.

In the future, direct transfer from hospital internal system to the BFCC registry is obligatory to integrate collaboration in the daily routine.

A follow-up app patients entering data on their own to gain more information on recovery process would be very interesting (PROM's). 80% feedback would be necessary to ensure significance and analysability. It has been discusses that this is a goal, but from experience, currently unachievable.



Items which describe the phenotype of the patient would be a benefit. Complete data entries are very important regarding the quality of the transnational registry as well as data security.

To be able to get information from the BFCC registry regarding post market surveillance would be a benefit for industry to be able to make statements with regards to treatment recommendations. The BFCC registry enabling research be providing special datasets would be worthwhile. The aim of the BFCC registry to deliver reports sharp in time to the hospitals was rated as very interesting and helpful for hospital and clinicians.

