

ADOPT BBMRI-ERIC GRANT AGREEMENT NO. 676550

DELIVERABLE REPORT

Deliverable no	2.6
Deliverable Title	Performance indicators for biobanks
Contractual delivery month	42
Responsible Partner	BBMRI-ERIC HQ
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PERFORMANCE INDICATORS FOR BIOBANKS

Executive Summary

BBMRI-ERIC is currently implementing its performance indicators. To monitor the overall performance of BBMRI-ERIC as a research infrastructure a series of performance, outcome, and impact indicators were established and approved by BBMRI-ERIC's Assembly of Members. The KPIs which were selected concern two major items that need monitoring on a regular basis. Firstly, the number of samples that is requested and shared is an important KPI for funders and biobanks to determine if the goal to share more and more is achieved and whether it's growing over time. Secondly, it is key for biobanks and National Nodes to monitor if and how often the developed services concerning Quality, IT and ELSI are being used. Also, here the trend should indicate significant growth. Since the structure of BBMRI-ERIC is complex and involves multiple layers it is at this stage hard to standardize already on the various KPIs, but this will be the goal for the mid/long term.

These key performance indicators are used as a guideline/direction for the National Nodes of BBMRI-ERIC but are not official measures for BBMRI-ERIC. Not all KPIs are relevant to all members and therefore no standard group is currently measured by each country.



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Document log

Issue	Date (yyyy-mm-dd)	Comment	Author/partner
D2.6.	2019-03-01	Initial version of the report	Erik Steinfeldler, Anna-Liisa Bader
D2.6_revised	2019-10-22	Revised version after Review Report	Erik Steinfeldler

1. Background

In order to implement BBMRI-ERIC's performance as a research infrastructure, certain performance, outcome, and impact indicators were established in 2016 and revised in 2017 and 2018 together with WP2, WP3 and WP4. These indicators serve to monitor the operation of BBMRI-ERIC and its improvement by executing the proposed work programme.

In addition, the National Nodes also started implementing these indicators on the national level as part of ADOPT BBMRI-ERIC project. This should help to better understand the actual deliverables in a member state, how they perform and if the focus is correct.

The focus of BBMRI-ERIC's KPIs has been widely discussed during ADOPT BBMRI-ERIC. During two BBMRI-ERIC scientific retreats (June 2015 in Austria and May 2016 in Greece) the different KPIs and their value to the community were discussed and summarized. The purpose of that summary was to have an initial set of performance indicators related to the vision, mission, and tasks of BBMRI-ERIC expressed in the BBMRI-ERIC Statutes. It aimed at providing ground for further discussions and consensus-gathering activities within the community and among its various stakeholders. The summary was reviewed by the Management Committee in June 2016 where it was concluded that this proposed set of performance indicators was excessive and served only as a cookbook for the selection of the appropriate ones, the most important of which will be established as the BBMRI-ERIC *key performance indicators*.

Also, in the beginning of the project, it was suggested to divide KPI to levels where different groups are responsible for different levels i.e.: first level: Graz BBMRI-HQ focus, then next level: BBMRI National Nodes, then biobanks further out.



2. Approach (methods)

One of the problems of devising a useful performance measurement system is trying to achieve some balance between having a few key measures on one hand or having many detailed measures (complex and difficult to manage, but capable of conveying many nuances of performance), on the other hand. Generally, a compromise is reached by making sure that there is a clear link between the operation's overall strategy, the most important KPIs that reflect strategic objectives and the bundle of detailed measures that are used to highlight each key performance indicator.

During two scientific retreats (in Austria in 2015 and in Greece 2016) a first selection was made on which KPIs could potentially be used to measure the performance of National Nodes and their biobanks. The focus shifted after the Assembly of Members meeting in Vienna on 8th of November 2017, where the parameters of BBMRI-ERIC HQ were approved and later used as guideline/direction for the National Nodes. This prevented ongoing discussions on which KPIs would fit best, without collecting them (reference AoM #11 minutes, point 5).

The main focus for National Nodes and their biobanks in terms of the key performance indicators is the number of sample requests and the number that could be supported and resulted in actual sharing of samples and their associated data. In order to have a reliable indication of the percentage of samples that have been requested, the total number of samples and the total number of requests per sample type were collected in several countries on a monthly basis.

For sample requestors it is key to understand the quality of the samples. To measure the total number of collections in biobanks, the total number of collections with a quality label and again the number of samples delivered were measured. This should give an indication on the importance of quality for the various requestors and an indication if there is a difference between quality needs and collection type. Within the National Nodes also the number of publications and involvement in scientific projects is still an often-used parameter to justify the investment in allocated resources related to the biobank. Next to quality services, the majority of the National Nodes is supporting biobanks with ELSI and IT related issues. On country and biobank level it is important to have data available on the actual usage of the services and educational support. Based on these numbers, budget and resources can be evaluated and allocated in potentially a different way in the future.

Besides scientific publications, biobanks invest in outreach activities to a wide group of stakeholders. Where the responsible persons for these activities in most cases have no background in marketing or communication, it is important which activities have been planned, executed and what the impact of these activities is. Social media currently offers off-the-shelf dashboards that guide you on a daily or weekly basis on the activities and their outcomes. This data is used in the dashboards for the biobanks and can guide in developing on one side more targeted strategies in outreach and on other hand can help build showcases between biobanks to share which approach worked best, supported by relevant data and trend analyses.

All KPIs were collected in close cooperation with the involved biobanks that are part of the National Node structure; it is important to emphasize that these key performance indicators serve as guidance and are not an official measure of BBMRI-ERIC. This is due to the diversity of BBMRI-ERIC Member



States: not all KPIs are relevant to all, and therefore no standard group is currently measured by each country. This approach will be reviewed in the future.

Generally, a compromise is reached by making sure that there is a clear link between the operation overall strategy, the most important KPIs that reflect strategic objectives, and the bundle of detailed measures that are used to highlight each key performance indicator, as also described in deliverable 1.6.

As a separate initiative BBMRI-ERIC participated in the ESFRI KPI Workshop in Milan on November 19-20, 2018, and coordinates the ERIC Forum project, where KPIs within Research Infrastructures are also on the agenda.

3. Results

The more in-depth implementation of the KPIs began after the Assembly of Members meeting in Vienna on the 8th of November 2017, where the key performance indicators were approved. They serve the community as a guidance and direction document; therefore, the document has not been made obligatory for all. If collecting structure data was not yet possible or not available, the Director General of BBMRI-ERIC scheduled monthly calls with the National Node directors to discuss the accomplishments of the country, their challenges and next steps, which gave solid and key background information per country that could be reported back to the Steering Committee. In addition, all member countries were visited in the period August 2017 – March 2019, with the exception of Norway, Malta and France.

In some cases, it was possible to measure access to the Directory and Negotiator per country and which collections were available. In the second half of the duration of the project also more Stakeholder and Quality performance indicators were measured, showing that activities were involving a wider audience.

Due to the complexity and long discussions on which KPIs to measure, the real measurements started relatively late. Therefore at this stage in most cases there was only relevant data available from one year, limiting our ability to see a trend in certain developments, e.g. increase in number of samples requested, collections that meet quality criteria or the number of publications related to biobank efforts. The collection of data will continue after ADOPT and contribute to a better understanding of the performance of an individual country in relation to biobanks.

As mentioned before, the KPIs serve as guidance and lack at this stage the opportunity but also support to truly compare the performance between biobanks and countries. Where the total number of biobanks, samples stored or publications written can differ in absolute numbers, the overall trends should be comparable and help countries to learn from each other's work, achievements and failures. Again, this will require more data over a longer period, but also certainly the willingness and openness from the various stakeholders involved. BBMRI-ERIC is committed to continuing the monitoring of key performance indicators after ADOPT has ended.

Appendix 1 contains an overview of some national-level KPIs. Serving the same kind of end users, there is still quite a difference in what is measured and how this is impacting the operational direction

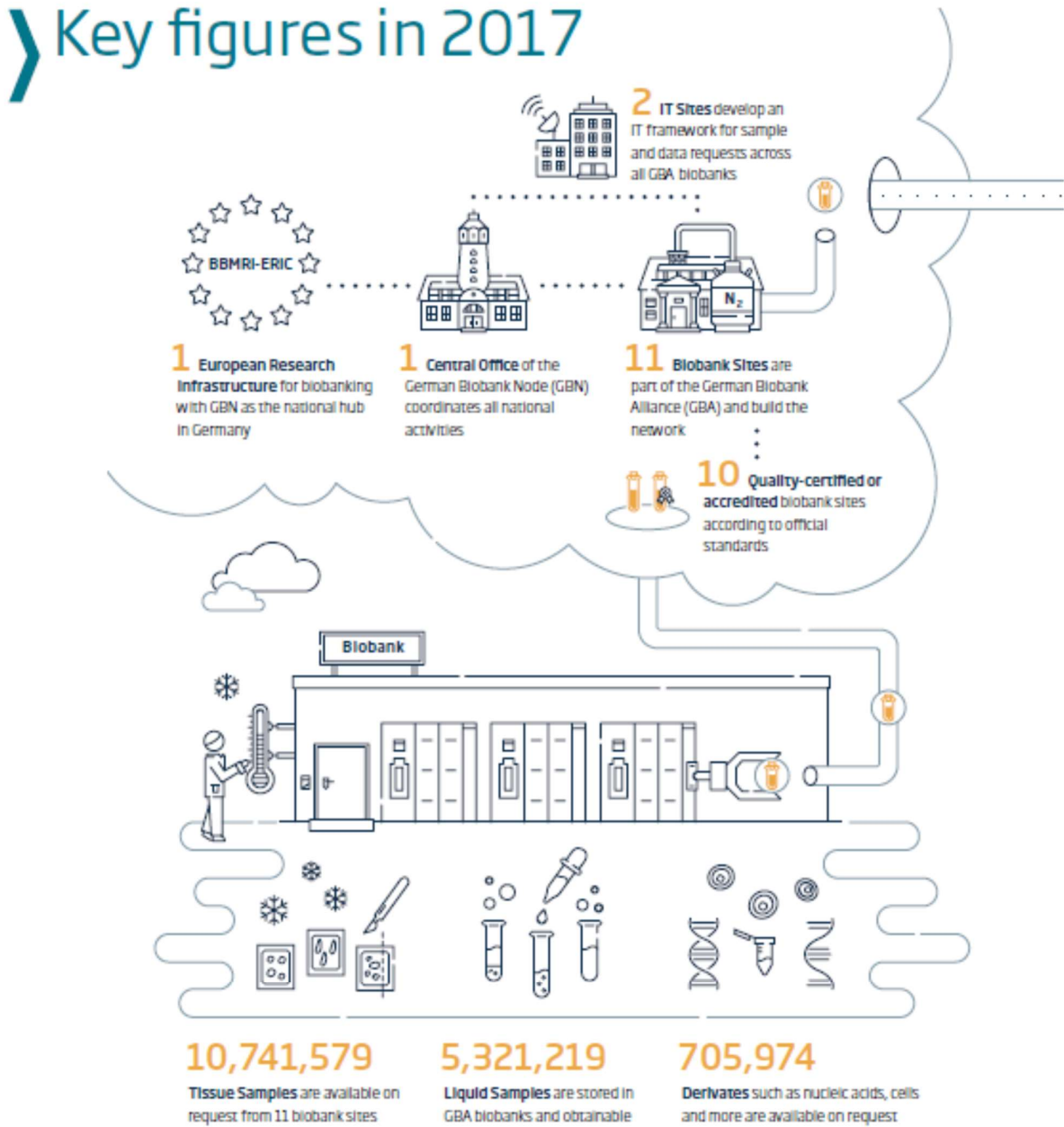


going forward. The success of the biobanks in Germany, Finland, Austria and the Netherlands is measured via the number of publications and projects in which they are involved. Here the total average number of publications is around 150, where the total number of samples that can be used, or the number of projects that is participated in can differ over 100%. It will be interesting to further explore the efficiency of project and publication involvement between the countries and their approach to making samples accessible.

The following figure is a graphical representation of the KPIs in Germany and how they relate to one another.



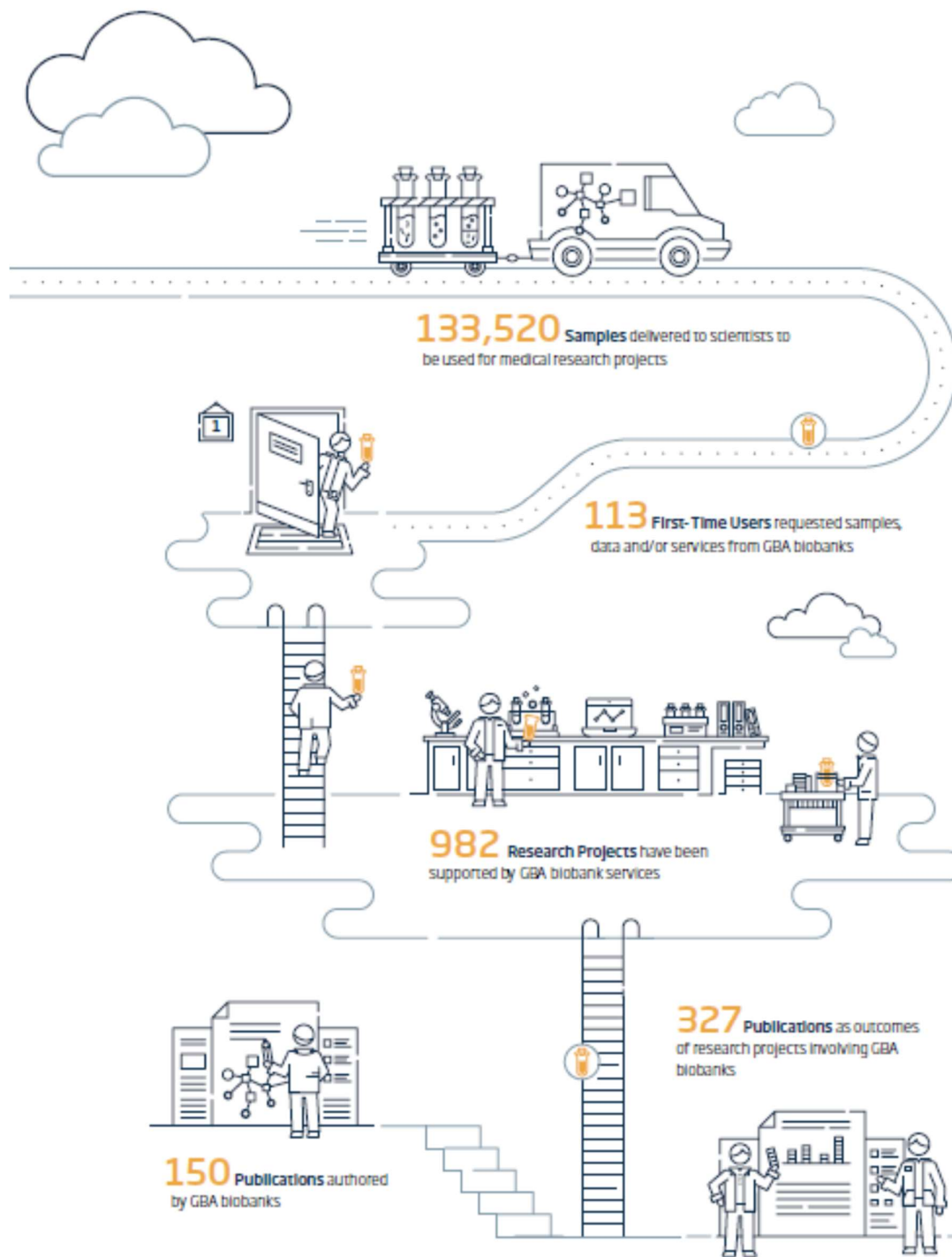
Figure 1. Graphical explanation of Germany's KPIs



One of the most important activities has been to define key figures for the biobanks. These key figures have been collected from all GBA biobanks and will be updated annually.



This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under grant agreement No 676550.



Appendix 1

Tables of National KPIs in Austria, Germany, Finland and the Netherlands

Table 1. Summary of the KPIs measured in Austria 2018

Samples	
Total biosamples in BBMRI.at at biobanks (estim *)	24,000,000
Total biosamples in BBMRI.at Catalog	19,362,894
New biosamples (estim**)	1,100,000
Scientists supported with	
Biosamples (estim**)	79,000
Projects (estim**)	130

Quality management	
Biobanks meeting CEN/TS requirements (status 2018)	3 (of 4)
Collections meeting CEN/TS requirements (status 2018)	5
Biosamples meeting CEN/TS requirements (status 2018) (estim**)	251,932
Biobanks cross audited by BBMRI.at QM	2
QM Experts in BBMRI-ERIC QM Expert Group	15

ELSI	
Public engagement (Number of public activities and non-scientific publications about biobanking/BBMRI.at)	14

Other	
Publications (estim**)	200
Number of on-site training sessions for technical biobank staff conducted	25

(estim) = because the many million archived samples (starting in the 1980s) of biobank Graz have not been counted in detail*

*(estim**) = because data are incomplete (estimations based were on developments over the past 2 years where possible)*



Table 2. Summary of the KPIs measured by German Biobank Node & German Biobank Alliance

General	
Structure of GBA = 1 Central Office (= German Biobank Node), 11 Biobanks, 2 IT Sites	
Available samples (on request)	
Tissue	10,741,579
Liquid	5,321,219
Derivates	705,974
Samples delivered to be used for medical research projects	133,520
Supported research projects by GBA biobank service	982
Publications authored by GBA biobanks	150
Publications as outcomes of research projects involving GBA biobanks	327
Number of organised Stakeholder Dialogue Forums	1
Number of participants who took part in Stakeholder Dialogue Forum	120
Number of workshops and webinars conducted	51
% of completed milestones/deliverables in time	90%

IT	
Number of biobanks connected to Sample Locator	15
Number of samples in Sample Locator	328,525

Quality management	
Number of quality-certified or accredited biobank sites	10
Conformity of the QM system of the GBA biobanks with the generic GBN QM manual	67%
Number of performed ring trials	2
Number of trained auditors for 'Friendly audits'	15
Number of downloads of QM manual published open access	2,320
Number of GBA biobanks which conducted the user satisfaction survey	13
Number of users interviewed in the satisfaction survey	532



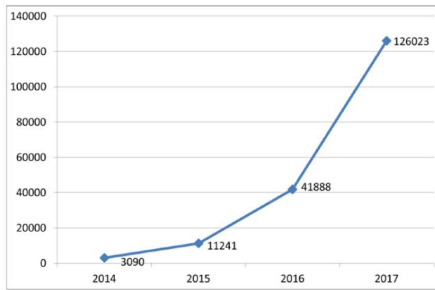
Public relations	
Number of page visitors (bbmri.de)	35,697
Number of website sessions (bbmri.de)	9,202
Number of Twitter followers (@bbmri_de)	284
Number of new Twitter followers (@bbmri_de)	211
Number of published success stories	3
Number of press releases published	3
Number of newsletter recipients	314
Number of newsletter editions published	5
Number GBA biobank sites using the GBN donor communication campaign	9
Number of distributed flyers/posters of communication campaign	8,000/ 150
Participation at congresses (with exhibition stand)	3

Education and training	
Number of on-site training sessions for technical biobank staff conducted	2

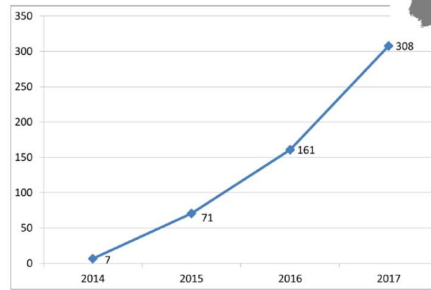


Table 3. Summary of the KPIs measured in Finland

Finnish biobanking activities are expanding



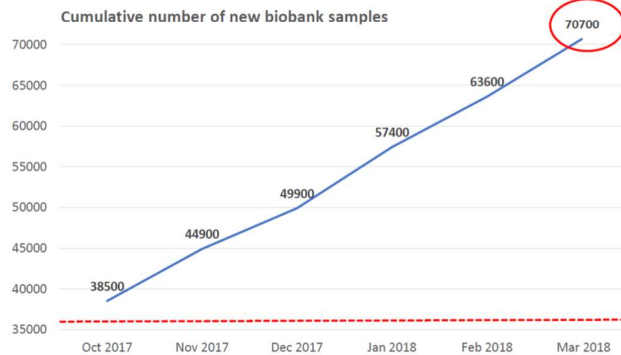
New biobank consents



Biobank access projects

Studies with biobanked samples and data resulted in 90 publications in 2017 !

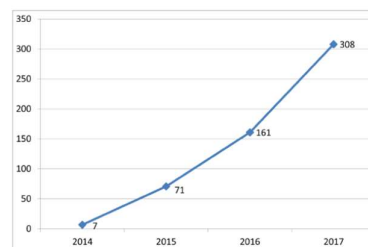
FinnGen project has boosted collecting new blood samples for biobanks



Picture from:
Anu Loukola, Helsinki Biobank

- Most current biobank projects are by the two first biobanks established in 2014

- **Auria Biobank :**
 - 46 % Industry driven biobank studies
 - 54 % Academic Research
- **THL Biobank**
 - 17 % Industry driven biobank studies
 - 83 % Academic Research



Biobank access projects



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Table 4. Summary of the KPIs measured in the Netherlands

General	2018
Number of papers where BBMRI-NL was acknowledged	150+
Number of Legal Consultations	1
Number of courses/workshops	4
Number of whitepapers, reports, books	3
Number of developed educational tools	4
Number of guides	1
Number of consultations Patient&Public Advisory Council	4
Number of BBMRI-ERIC collaborations	2
Communication and outreach	
Number of BBMRI e-newsletters	2
Number of subscribers BBMRI e-newsletter	571
Number of website sessions	10,000+
Number of social media actions (tweets, retweets, likes, shares, links, posts, replies)	600+
Service Platforms	
Number of registered users Servicedesk (all services)	3551
Number of sample- and/or datacohorts in Catalogue	279
Number of new sample- and/or datacohorts in Catalogue	27
Number of Catalogue visitors	700+
Number of Requests National Pathology Data and Tissue Portal	354
Number of Requested Pathology Tissue Blocks	5000+
Number of samples with methylome, transcriptome and metabolome data in Omics dataset	4012
Number of users Omics dataset	600+
Number of websessions ELSI Servicedesk	3755
Number of detailed FAQ's on website ELSI Servicedesk	44
Number of customized answered questions ELSI Servicedesk	14
Number of accounts DPIA App	80
Number of started procedures DPIA App	2000+

