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ToolPool Gesundheitsforschung – A Repository for Software and Services Focused on Supporting Clinical and Epidemiological Research

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Abstract. The academic research environment is characterized by self-developed, innovative, customized solutions, which are often free to use for third parties with open-source code and open licenses. On the other hand, they are maintained only to a very limited extent after the end of project funding. The ToolPool Gesundheitsforschung addresses the problem of finding ready to use solutions by building a registry of proven and supported tools, services, concepts and consulting offers. The goal is to provide an up-to-date selection of "relevant" solutions for a given domain that are immediately usable and that are actually used by third parties, rather than aiming at a complete list of all solutions which belong to that domain. Proof of relevance and usage must be provided, for example, by concrete application scenarios, experience reports by uninvolved third parties, references in publications or workshops held. Quality assurance is carried out for new entries by an agreed list of admission criteria, for existing entries at least once a year by a special task force. Currently, 79 solutions are represented, this number is to be significantly expanded by involving of new editors from current national funding initiatives in Germany.

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1. Introduction

Medical research has been working across locations and multiple disciplines for many years. Extensive knowledge of the needs, but also of the available solutions, is of great importance when planning and setting up new projects, especially larger research networks and their respective IT infrastructure. At the same time, due to the multitude and complexity of tools, a single researcher can hardly keep track of timeliness, readiness for use and market penetration of a product. The ToolPool Gesundheitsforschung (ToolPool Health Research: https://www.toolpool-gesundheitsforschung.de) aims to provide a list of maintained and currently used IT solutions in various domains in clinical research. The goal is not to cover the tools of a research area as completely as possible, but to provide a sufficient overview of solutions in a given domain that can be used and are actually used by third parties. It strives to meet the needs of different stakeholders and thus distinguishes itself from purely technology-oriented platforms, but the primary user is not expected to be an ultimate expert in the domain but someone whose task it is to research deployable solutions that need to be evaluated in more detail as part of the future research project.

The TMF [3] is the umbrella organization for collaborative medical research in Germany. It is a platform for interdisciplinary exchange and cross-site collaboration. Its members are university institutes, clinical study centers, cohorts, research networks or individual third-party funded projects. Solutions and recommendations for medical research are developed from the collaboration in the TMF working groups. The TMF is also active as a partner in national and European research projects. As a result of this work, software tools, white papers, legal opinions, generic concepts (e.g. on aspects of data protection, on the legally secure operation of biomaterial databases or on patient consent) as well as training and consulting services are created.

The TMF's range of topics is broad and results from the demands that technological and scientific advances place on medical research institutions. A central aspect of this is the support of its own members, as well as the general research community, in setting up and operating the IT infrastructures required for research activities. The focus is on supporting the strategic planning of an overall IT solution by providing concepts and consulting services, not on the actual implementation or operation [1].

The background to this strategy is the frequently made experience that the establishment of larger research networks is difficult for the persons involved, despite the fact that the tasks are always recurring across the board. The individual organizational units use complex systems, and their results build on each other. Given the large number and heterogeneity of topics, interdisciplinary knowledge cannot always be available in the necessary breadth and level of detail.

At the same time, time constraints make it impossible for the members of the working groups to respond in a comprehensive manner to inquiries or drafts at all times. So far, work has focused on the one hand on reports from current projects and on the other hand on such solutions that have been developed within the TMF. In recent years, it has become clear that this form of exchange and presentation of solutions does not lead to sufficient transparency of the best tools and services available in this area. In particular,

[3] https://www.tmf-ev.de/EnglishSite/Home.aspx

hardly any externally developed solutions have been listed on the TMF website. Furthermore, no information about the use of the products and the experiences made with them was available beyond the developing group. Some products were no longer maintained after the end of the project, and thus no longer met the requirements for productive use. Finally, the experience had to be made that due to changing personnel even in the TMF membership, too many of the available information and support services were unknown.

All these points resulted in the need to upgrade the TMF's dissemination concept and the idea of a much broader focus in terms of content. Based on the experiences and discussions in the relevant working groups - especially IT infrastructure and data protection - and events organized by the TMF, the initiative to build a web-based information platform emerged. The platform aims to bundle all existing resources in a central place, to support users with different levels of knowledge in planning an IT infrastructure for their collaborative research projects, and to guide and accompany more intensively especially in the selection of the most suitable tools to be used in a project. Furthermore, it should be open for the presentation of external academic and commercial solutions, enable a better findability and more comprehensible presentation of the solutions, encourage evaluations and experience reports and finally initiate an exchange of researchers among themselves, which flanks the consulting offers of the TMF working groups.

2. Methods

The main mission of the TMF is to support clinical research mainly through collaboration of its members in organizational structures such as the working groups. Based on the nature of the project, the TMF working group IT Infrastructure and Quality Management (WG IT-QM) was selected as a partner. The project went through three phases: a planning phase, an implementation phase, and an evaluation and population phase.

In the planning phase, based on a comprehensive benefit and environmental analysis, a draft concept was created by TMF office staff and discussed in the WG IT-QM [2]. At the same time, an experienced external agency[4] was selected and involved to support the further concept development methodically and with regard to the later presentation form as well as the necessary functionality of the intended web platform. On the basis of the first concept and the discussion results of the WG IT-QM, various target groups were determined. Pre-structured telephone interviews were conducted with two selected representatives of each of these target groups. The results of these interviews were used to plan two conceptual workshops with experts from various TMF working groups and the TMF office. In the first workshop, the four main target groups and their requirements were described in more detail and summarized in personas [3]. These formed the foundation for the description of user scenarios and the elaboration of the requirements analysis in the second design workshop. Based on the analysis of user requirements, the agency developed a navigation concept and the description of the most important functions and features of the planned information service in close cooperation with the TMF office. Individual central user interactions were described and recorded in exemplary sketch form (wireframes).

[4] https://3pc.de/

In the implementation phase, the concept was realized with the help of an external partner, who was able to provide a fast and feature-rich solution due to its extensive experience with similar information portals. Furthermore, the company can be commissioned promptly for further developments if required. The TMF members clearly see their core competence in the scientific area and not in the contract development of software.

A comprehensive validation of the technical platform was performed in the evaluation and population phase on the basis of existing information content from the TMF product list[5]. This list includes results of TMF's own projects and thus also strengthens their visibility and sustainability. This was followed by a broad call for participation in the TMF member networks. For the selection of products, a separate governance process was agreed upon (see 3.3), according to which drafts can be submitted non-discriminatory, but must be confirmed by a quality assurance procedure. Then, editors were recruited and product records (software, services, expert opinions, consulting services, training) were entered. The result was presented internally and externally in various ways and active participation was solicited [4].

3. Results

3.1. Information architecture and technical implementation along target groups

As a result of the described approach, a web-based portal was realized by specialists of this type of applications[6]. The technical basis is the content management system Drupal[7]. With the help of this framework, complex websites can be implemented. Free-text sections and structured content can be combined. Drupal is a well-established system, and most of the required technical functions such as design templates, collaboration, role-based access control, versioning, search function and others are supported out-of-the-box. Various entry pages and consistent user guidance take into account the different information needs in each case. The following target groups are specifically addressed in the portal:

- *Coordinators/managers* of a medical research network: responsible for planning (e.g., application) and setting up infrastructures (start-up phase of the project), but also decision-makers in the working phase.
- *IT officers* in collaborative medical research projects: Medical IT specialists or even physicians who specialize in IT issues want a quick start, for example, via a search, and then further information on concrete detailed information such as programming languages, interfaces, standards, etc.
- *Scientific staff* in medical research projects: as non-IT specialists, they need clearly prepared information on the technical, organizational and legal-ethical requirements and usage scenarios.
- *Employees of funding organizations and reviewers*: require information on the acceptance of ongoing projects, e.g. for reviews, as well as on the current need for further development of IT infrastructures, in order to be able to initiate corresponding funding calls.

[5] https://www.tmf-ev.de/Produkte/
[6] https://www.outermedia.de
[7] https://en.wikipedia.org/wiki/Drupal

Suitable navigation hierarchies and alternative ways of access were realized for the different target groups. Thus, in addition to a common listing of all products, a presentation along typical project phases is also offered as well as a thematic categorization based on the chapters of the TMF IT report [1]. In addition, the portal was given a search function that also allows a step-by-step narrowing of the result set via a detailed selection of facets and thus another alternative type of navigation.

3.2. Collaboration and community functionalities

A special focus lay on the implementation of community functionalities, which should allow TMF experts to easily contribute to entries as well as provide user convenience features:

- A single sign-on solution with the TMF website reduces the threshold of an additional registration on the new platform, at least for the community active on the TMF website with about 4000 registered users. Because transparency is needed about how and by whom the information presented was created, and because users of the portal want to get in touch with users of existing tools, contact persons and editors are distinguished by their real names.
- Adding a new product is possible for any registered user using a form that collects structured information on the individual sub-items (see 3.3).
- Shared experiences are a key unique selling point. The portal offers the possibility to publish an experience review for each product. This helps future users to decide whether the product is suitable for their requirements. Furthermore, users can write comments on all product records. Comments are moderated by an editorial team.
- Logged-in users can create an info basket to mark products and other pages and share them with colleagues and project partners. In addition, registered users have the option of subscribing to relevant pages to be informed about changes in content.

3.3. Governance process

The goal of the ToolPool Gesundheitsforschung is not a complete representation of all existing products of the application domain as in an encyclopedia. Rather, the aim is to provide an overview of the relevant solutions. While a necessary minimum number of entries is desirable, careful consideration must be given to which products should be included, especially since conflicts of interest cannot be ruled out in every case. For this reason, a criteria catalogue has been developed and published, which clearly sets out the necessary requirements for the inclusion of new solutions[8]. These essentially correspond to the ideas already outlined, such as domain relevance, availability/licenses, documentation, technical requirements, information on deployment, information on maintenance, service level, product age, and references to external sites such as scientific publications, workshops performed, awards, or other important links.

As the operator of the ToolPool, the TMF does maintain strict neutrality while ensuring high quality content. For this reason, a board of trustees was created to accompany the operation and, in particular, to select and present the topics and new

[8] https://www.toolpool-gesundheitsforschung.de/ueber-das-portal/kriterienkatalog

products[9]. It is composed of members of the WG IT-QM and the IT Reviewing Board as well as representatives of the TMF Board and an editorial team in the TMF office. The decision is thus in the hands of a democratically constituted body of the academic research community. To ensure permanent compliance with the criteria for existing products, a task force reviews all entries annually.

4. Discussion

Since the launch of the portal in March 2017, there have been more than 24,018 visits of the website until January 2022 with more than 58,117 page views in total. Figure 1 shows a telling example of one of the ToolPool's product records, the 3LGM² toolbox. It is an application designed to support strategic information management in modeling health information systems. It is based on the Three-layer Graph-based Meta Model (3LGM²) [5]. Although it has been actively and continuously developed for a long time [6], it naturally has a narrower target group than generic modeling tools such as ARIS [7] and is therefore less visible in the community. Newcomers to information systems modeling or those responsible for modeling their research network are now faced with the question whether the tool is suitable for their use case and whether it is worth the effort to learn it. There are typical risks such as low dissemination, insufficient documentation, and proprietary formats. With the help of the TMF ToolPool it becomes clear that the toolbox is still being actively developed, it is being used in various projects, training and tutorials are offered, and common standards like Integrating the Healthcare Enterprise (IHE) are supported [8–11].

Currently, 82 products are listed in the ToolPool, divided into six categories: software, eService, report/legal opinion, working material/checklist, consulting and training (see Table 1).

Table 1: The number of products per category published in the portal (last accessed on 2021-04-06).

Product category	Software	eService	Working material/ checklist	Report/legal opinion	Consulting	Training
Number of products	43	12	10	7	5	5

Although this is a solid foundation, the range of information, tools and applications still needs to be broadened to meet the needs in the biomedical research community. The content creation needs to be done manually. In order to achieve more product entries, a broader range of editors needs to be recruited. The many current funding programs in Germany, including the Medical Informatics Initiative [12], the National Research Data Infrastructure (NFDI)[10], which is currently being established, or the Network University Medicine (NUM)[11], lend themselves to this. All these initiatives come into consideration both as users and as providers of their solutions. In addition, projects could already commit to a ToolPool entry of project results in their applications for reasons of sustainability. In this context, the ToolPool's incubator area for solutions and products still under development could also be helpful.

[9] https://www.toolpool-gesundheitsforschung.de/index.php/ueber-das-portal/kuratorium
[10] https://www.dfg.de/en/research_funding/programmes/nfdi/index.html
[11] https://www.netzwerk-universitaetsmedizin.de/

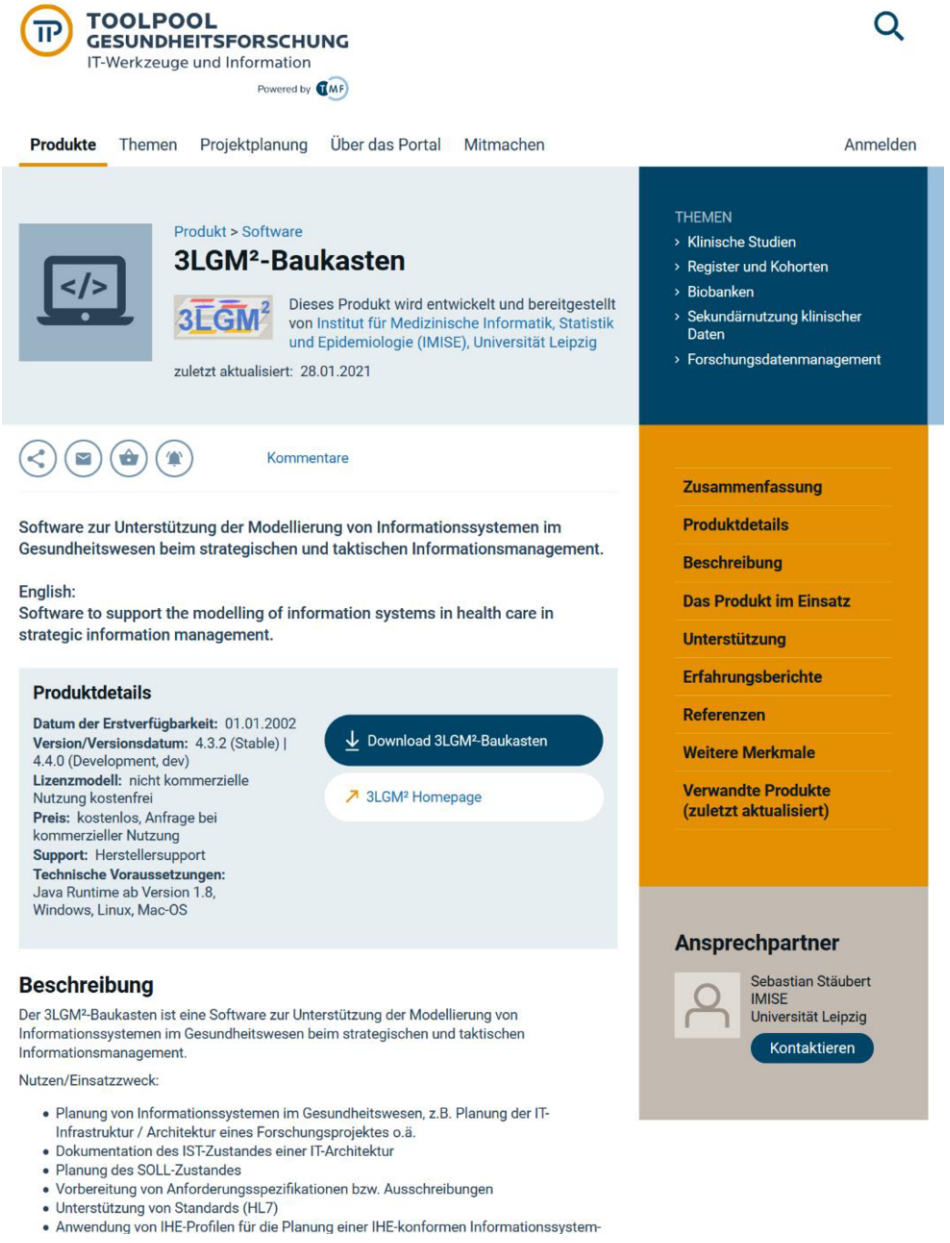

Figure 1: Section of an exemplary entry for a software product in the ToolPool Gesundheitsforschung (image slightly cropped for clarity).

Currently, there is only a German version of the portal with a short English summary per product entry. To address also partners in European projects, a semi-automatic English translation should be considered here, also with a view to the European Open Science Cloud (EOSC). Further potential for improvement lies in the content area, for example, particularly recommendable products could be awarded as preferred variants by the research community. Potential for improvement can also be identified at the technical level, particularly with reference to the FAIR principles (annotation with machine-readable vocabularies). For example, the FAIR for Research Software (FAIR4RS) WG[12] of the Research Data Alliance is currently developing guidelines how to apply the FAIR principles for research software.

A number of portals exist that share certain goals of the TMF ToolPool, but have different foci. For example, within the EFMI working group LIFOSS, a "comprehensive and structured overview of Free/Libre and Open Source Software projects in the domains of medical informatics and health care delivery" called Medfloss[13] is maintained, but this requires solutions to be software and open-source. In Bioinformatics, bio.tools[14] and de.NBI[15] host similar listings, but they are not focusing on clinical and epidemiological research. ELIXIR-EXCELERATE, on the other hand, drive early user exploitation projects across the life-sciences rather than mature solutions. The Software Sustainability Institute runs a program called Research Software Healthcheck[16]. Here, experts "check your research software to exploit its potential and make it more sustainable". But this is more targeted at coaching for a handpicked number of products. Furthermore, there many commercially-oriented listings e.g. the Virtual Market Place®[17] of the DMEA (Digital Medical Expertise & Applications), Europe's largest fair in the domain of health IT.

5. Conclusions

The ToolPool Gesundheitsforschung supports research projects in setting up a suitable IT infrastructure. Users especially benefit from the exchange of a wide variety of players who share their solutions and experiences in the portal. At present, there is a stable basic stock of current, relevant and quality-assured products. To ensure sustainable operation, improvements must be made in the number and range of products as well as in features the portal offers. In this year, we will start a surge for new editors and assets from various networks, particularly from the current national funding initiatives in Germany, such as the Medical Informatics Initiative, the German Centers for Health Research, the development of a National Research Data Infrastructure or the University Medicine Network, being all a source and a target group for our approach.

[12] https://www.rd-alliance.org/groups/fair-research-software-fair4rs-wg
[13] https://www.medfloss.org/
[14] https://bio.tools/
[15] https://www.denbi.de/categories/software-libraries
[16] https://www.software.ac.uk/news/complete-international-rse-survey-and-help-us-understand-rse-community
[17] https://www.virtualmarket.conhit.de/

Declarations

Conflict of Interest: The authors declare that there is no conflict of interest.

Author contributions: ML: conception of the work, data acquisition and interpretation, ML: writing the manuscript, TG, US, SS, JB, KK, SH: revising of the manuscript. All authors approved the manuscript in the submitted version and take responsibility for the scientific integrity of the work.

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