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National Research Data Infrastructure
for personal health data

D4.8 Web-based citizen science research data portal

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Task Area 4 and T4.5

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Dissemination Level	
Public	X
Defined public group	
Within consortium	

☐ For software deliverables: The functionality of the code is approved by TA and TA-Leads.

☒ The TA leads reviewed and approved this version of the deliverable report before it was submitted to the coordination team for information.

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D4.8 Web-based citizen science research data portal

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Introductory Statement

This deliverable reports on the development process of the pilot version of the NFDI4Health *ResearchDialogue* portal and the results achieved. It is considered to represent the successful implementation of the respective objective for T4.5 as outlined in the project proposal.

During the development process, numerous additional issues and possible further development avenues were identified, some of which are outlined in the outlook section. These will be pursued during the remainder of phase 1 of the NFDI4Health project.

Goal

The aim of this project was to develop a web-based, interactive platform for information exchange in the healthcare domain, focussing on research studies either completed or in progress. The platform was designed to support an increase in the participation of various stakeholders, including citizens (such as patients, relatives, and interested individuals) as well as scientists, in accessing health data and studies through easily accessible and barrier-free information offerings. The information provided originates from studies listed within NFDI4Health, notably from the German Central Health Study Hub (CSH). This information is made available on the platform by the respective study authorities in conjunction with and addition to entries in the CSH.

Introduction

TA4 addresses two target groups: (a) the whole interdisciplinary NFDI community (T4.4), representing scientists and clinicians in (bio)medical research, and (b) citizens and patients, whose continued active participation (T4.5) is essential to increase public acceptance of sharing sensitive personal data for health research, to improve understanding of the benefits of data re-use, and to increase trust in the secure handling of these data. The main work in T 4.5 focuses on group b), while members of group a) are important as providers of information and content and as partners for interactive exchange.

Involving citizens and patients in the overall work of the consortium will be the core objective of this measure. Participatory processes form a key component of integrated knowledge translation. This has become a cornerstone of implementation-oriented health research (Gagliardi et al., 2017).

Within T4.5, this objective was achieved through the conceptualisation of a web-based citizens' portal through which citizens can obtain an overview of a selection of the studies listed within the CSH.

The original idea of integrating access to personal data in order to get an overview of one's own research data collected in a study and to be able to view the terms of use for handling one's own research data (e.g. data protection regulations, application procedures, overview of studies that have used one's data) was discarded as it was not deemed feasible within the NFDI4Health framework where no primary study data are managed by the consortium. This also applies to the original idea of being able to search one's own data. The approach of developing and recommending research questions suggested by the public still exists and some features of the *ResearchDialogue* portal already address this idea.

What is a (digital) Portal?

The lexical definition of a portal describes a door, passageway or entrance area that allows entry into a large and/or grand building (Oxford English Dictionary; Reference), thus providing access to a new, separate area. This meaning can also be applied to the digital infrastructure. In this context, a portal describes an access route to (specific) knowledge and information on the Internet (cf. Oxford English Dictionary).

The literature distinguishes between different types of portals (Dias, 2001). In the early 2000s, a heterogeneous definition of the term portal emerged, but central access to a range of functions can be summarised (van Brakel, 2003). Public portals address a wide range of individuals and provide (unrestricted) access to portal-specific content (Dias, 2001). Over time, these portals have evolved into personalised and interactive websites. Information and content portals are classified as public portals. The aim of these portals is to organise and collect specific content that can be targeted using an integrated search function (Dias, 2001; Murray, 1999).

Patient portals, initially developed in the 1990s (Halamka et al., 2008; Mandl et al., 2007; Irizarry et al., 2015), gained significant traction around 2006 (Weitzman et al., 2009). These systems, mostly offered by healthcare institutions, allow patients to access electronic health information, including their electronic health records (EHRs) (Ammenwerth et al., 2012; Bourgeois et al., 2009; Izarry et al., 2015; Lockwood et al., 2018; Turner et al., 2019). They facilitate doctor-patient communication and offer advantages over paper-based information by enabling digital access and linkage to online resources. Studies demonstrate positive outcomes such as increased patient participation, satisfaction, and treatment adherence (Ammenwerth et al., 2012; Lauren et al., 2021; Tulu et al., 2016; Dendere et al., 2019; Kruse et al., 2015). However, usage tends to be higher among younger, chronically ill individuals with greater eHealth literacy (Hoogenbosch et al., 2018).

During the COVID-19 pandemic, there was a surge in "open health data," sourced from public authorities and including clinical and survey data (Wu et al., 2021). This led to the establishment of networks and portals facilitating unrestricted access to machine-readable health data. Stakeholders, including patients, governments, and medical institutions, sought such platforms to track disease development and spread (Ji et al., 2013; Wu et al., 2021). Consequently, there is a growing demand for advanced and user-friendly health data portals (Wu et al., 2021).

Procedure and methods

The layout was developed internally according to the corporate design of NFDI4Health, and oriented towards the "Research Data Portal for Health" of the “Medizininformatik-Initiative”. Content aspects of the website were developed by members of T4.5. Specific study information was provided by the study managers using a standard information template. T1.3 provided editorial support for this process.

The template presented in Table 1 was developed after a review of best practice examples and scientific evidence synthesis (structured literature search and evidence synthesis following the principles of a scoping review). The review sought to identify the digital methods and tools employed for information exchange between patients/public and researchers. Additionally, it explored the preferred modes of interaction and the types of information or data that are available and of interest to the public. The manuscript of the scoping review will be ready for publication submission by July 2024.

Table 1: *Structure of desired information template*

Element	**Description**
Project name	Free text
Teaser (for tile description)	3 sentences in plain language
Bullet points	Max 10 bullet points describing the research project in plain language

Summary	Summary of research project in plain language (max 300 words)
Project goals	Max 300 words in plain language
Results	Describe main results (or expected results) in plain language
Results: graphs, illustrations	Image files
Project dates	Start and end date
Contact	Name, email address
Keywords	Simple keywords most relevant to the project
Project partners	Main partners (institutions), logos as attachment
Further information	URL for detailed information

Results

Currently, the *ResearchDialogue* portal includes two studies selected from the Central Study Hub (CSH) study catalogue as a pilot implementation. The information template is implemented and contains descriptions and explanations that help website visitors to understand the research project in plain language. The portal can be used for interaction between citizens and patients and the persons responsible for the study, mediated through the portal host, i.e. NFDI4Health. The interaction is currently limited to a simple feedback option. The portal is available in German and English language.

Figures 1 to 4 are screenshots of the current iteration of the *ResearchDialogue* portal. Figure 1 shows the navigation from the NFDI4Health homepage to the *Community* menue and the *ResearchDialogue* portal. An explanation of the main objectives (see Figure 2) can be found on the *ResearchDialogue* portal webpage (Figure 2). It also presents the studies listed in the portal (currently including the I.Family and Corona KiTa studies).

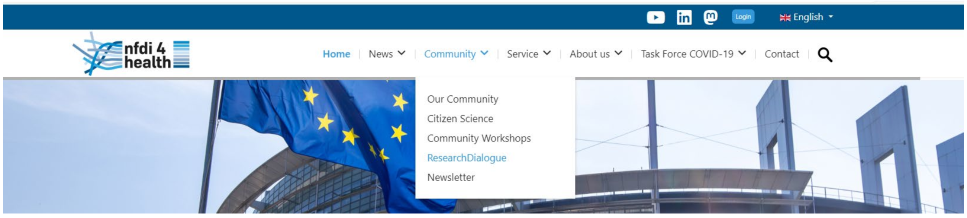


***Figure 1:** Navigation to the ResearchDialogue portal from the NFDI4Health homepage*

ResearchDialogue - Shaping Health Together

The ResearchDialogue Portal provides the public with comprehensible information on research projects and studies. It contains descriptions and explanations that help people to understand our research. We would like to use this portal to enter into a dialogue with our citizens and patients. The portal is part of our citizen science approach that is important to us in order to receive feedback from the public. In the near future, you will also find information here on studies and research initiatives in the field of health that are particularly geared towards exchange and cooperation with citizens.

***Figure 2:** Appearance of the ResearchDialogue portal after selection from the NFDI4Health website control bar*

The detailed presentation of a study according to the information template (see Table 1) is shown in Figure 3. The design includes a reduced use of text and a prioritised communication of study information using pictograms and bullet points. The study objectives are depicted in a simple sequential presentation. The results are communicated using the pictograms shown.

Portal users also have the opportunity to provide feedback on the study and information (see Figure 4).

ResearchDialogue_I.Family

You are here: Community / ResearchDialogue / ResearchDialogue_I.Family

I.Family - determinants of food choice, lifestyle and health

Start date	End date	Participants	Main goal
March 2012	Juli 2017	over 10,000 children in Europe	Promotion of healthy eating behaviour

Summary

Building on data gained from over 16,000 children in the IDEFICS study I.Family provided further insight into the most important influences on Europe's young people, their lifestyle behaviour and their eating habits. The project's acronym – I.Family – highlights the project's focus on both the influences on the individual and on their family. I.Family did this by re-assessing families as their children moved into adolescence, identifying those families that have adopted a healthy approach to food and eating habits and those who have not. The project helped us understand the biological, behavioural, social and environmental factors that drive dietary behaviour as children journey towards adulthood.

Person responsible for the project: Prof. Dr. Wolfgang Ahrens (i.family@leibniz-bips.de)

What do we want to achieve?

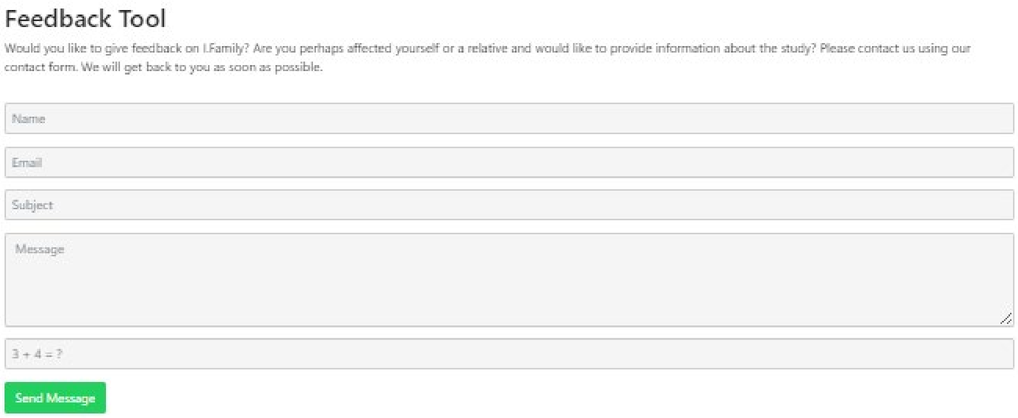
1 Understanding the interplay between barriers and main drivers of a healthy food choice.

2 Identifying predictors of unnecessary weight gain and cardio-metabolic risk by linking them to diet, physical activity and interacting factors.

3 Developing and conveying strategies to induce changes towards a healthy behaviour

Results

Figure 3: *Detailed presentation of the I.Family study in the ResearchDialogue portal; implementation example of the information provision template and its aspects from Table 1*



Feedback Tool

Would you like to give feedback on I.Family? Are you perhaps affected yourself or a relative and would like to provide information about the study? Please contact us using our contact form. We will get back to you as soon as possible.

Figure 4: *Study-specific feedback return option in the ResearchDialogue portal*

The current implementation of the ResearchDialogue portal represents an early version of an information portal that contains important functions of a study information exchange. This facility allows for a closer exchange between the public and the scientific community by offering users the opportunity to obtain processed health research information without necessarily having to participate in a specific study. In addition, the portal provides an opportunity to contact and provide feedback, which creates a low-barrier communication option and allows for more in-depth discussion of scientific results and studies beyond the information presented.

Further development and evaluation

First external feedback was received during the workshop "Gesundheitsforschung: Wie können meine Daten helfen?" held in Oldenburg on April 9, 2024. Overall, the feedback was positive, but concerns were raised about the quality of evidence and trial result information presented. The feedback providers were scientists specializing in information processing and research related to patient involvement in clinical trials, with expertise in patient interaction with digital technologies. In addition, the evaluators praised the *ResearchDialogue* portal for its innovative approach and appreciated the visual accessibility and clear structure of the site.

With regard to the above concerns, T4.5 cannot verify the scientific accuracy of the results of each trial, so we rely on trial principles based on peer-reviewed publications and the reputation of the publishing institute. This ensures a solid foundation for our data interpretation.

An important milestone in the development of the portal is a formal sequential quality assurance process. This is currently carried out through the submission of study information in German and

English, using the appropriate template, by those responsible for the study. This information is reviewed by the staff of Task Area 4, T4.5, and checked for relevance and comprehensibility by the editorial team of the NFDI4Health website for editorial review and entry into the portal.

Regarding aspects of evaluation of the portal, there is a first concept for a user survey for the participatory development of the *ResearchDialogue* portal. This survey will include a presentation of the current status including a demonstration of the use of the website (navigation from the homepage to one of the two studies listed). Users will also be asked why they visit such a portal based on subjective needs, whether potential needs have been met and whether the website has an attractive design. The subjective user experience and the design will be collected in the survey using the standardized survey instruments *Perceived Website Usability* (PWU; Flavián et al., 2006) and the *Visual Aesthetics of Website Inventory* (VisAWI, Moshagen & Thielsch, 2010, 2013), both in their German versions. The target group of the survey should be citizens and/or patients who have no significant experience in dealing with relevant information portals or websites.

In addition, the idea is to conduct guided intensive use of the NFDI4Health website through focus groups or guided interviews, and to identify potential pitfalls in this process (from finding the NFDI4Health website through a Google search query, to viewing the studies listed in the *ResearchDialogue* portal and providing feedback). A guideline, recruitment strategy and evaluation parameters have yet to be developed.

Outlook

The next steps with respect to adding further value to this deliverable entail the following:

- More prominent featuring of the *ResearchDialogue* portal on the NFDI4Health Website, to increase findability by the target group.
- Further evaluation of features by the citizens, study participants and others
- Strengthening of interactive features, including quiz-type approaches
- Addition of further studies and providing reference to the NFDI4Health citizen science project funded in the 2023 call.
- Developing of a manual to systematically describe the process of plain language presentation of research for low- threshold communication.

Summary

T4.5 established a pilot information portal – the *ResearchDialogue* portal - according to the tasks listed within the proposal. The pilot version of the *ResearchDialogue* portal presents an information portal that integrates study information exchange functions, providing access to multiple studies conducted on this topic.

The portal facilitates public integration into the scientific community by offering processed health research information in plain language and a low-barrier communication option for contacting and providing feedback. In principle, this enables more in-depth discussions of scientific results and studies beyond the presented information, but more information and user feedback on actual uses is required.

The web-based citizen science data portal is part of a wider approach to support citizen/patient involvement and participation. This includes the presence of citizen/patient representatives in the User Advisory Board (UAB), who have experience as research participants. They regularly interact with the consortium and contribute citizen/patient views and insights into relevant issues around data provision and usage. The pilot version of the portal will be expanded to include interactive elements specifically designed for patients and the public, not only to provide information on the work of the consortium, but also to include user quizzes, surveys and/or new video sequences to support active engagement in NFDI4Health activities. Publicity will be orchestrated in close collaboration with T1.3, particularly through social media. As a further step, a citizen/patient involvement evaluation framework will be developed to assess, inform, and adapt the work of the consortium from a citizen/patient perspective.

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