

Governance of Smart Food Intake

Deliverable Smart Food Intake Work Package 7

Trond Selnes



WAGENINGEN
UNIVERSITY & RESEARCH

VERTROUWELIJK

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Smart Food Intake is een project om data over voedselinname en onderliggende motieven op een verbeterde, betrouwbare, toegankelijk en up-to-date manier te verzamelen. Een flexibel, modulier systeem dat gebaseerd is op de 2-uurs recall-methode ('snapshot') is ontwikkeld om dat doel te bereiken. Deze methode zal het voor de voedingsindustrie en de onderzoeksgemeenschap mogelijk maken de gegevens over voedselinname sneller, flexibel en op een meer betrouwbare manier te verkrijgen. De modulaire en flexibele methode zal het mogelijk maken om uit te breiden naar andere eetcontexten, doelgroepen en landen.

Smart Food Intake is a project to improve the collection of reliable, accessible and up-to-date food intake data and underlying food choice motives as important determinants of food intake. A flexible, modular system based on the 2-hour recall ('snapshot') methodology was developed to reach that aim. This methodology will enable the food industry as well as the research community to collect data on food intake in a faster, flexible and more reliable way. The modular and flexible method will make it possible to expand to other eating contexts, target groups and countries.

Key words: food intake, food choice motives, data management, GDPR, FAIR, governance

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Preface

Smart Food Intake is an important stepping stone for research on how to stimulate more healthy and sustainable food consumption as it helps to gain better insight into food consumption and its determinants. The importance is also related to the fact that this is a public-private, pre-competitive, collaboration, which allows the partners to focus on the joint character of the project. For both the food industry and WUR the need for a more advanced methodology, with new data collection methods for food intake and its determinants, has been a driving force behind the project. Most of the effort was oriented towards the methodology and the app that was used to develop the understanding needed. But the project also contained a work package on governance, which was meant to identify and elaborate on relevant issues related to the matter of how collaboration on tools, data and services should or could be approached. Some of these issues exceed the level of a single project and were never meant to be decided upon within the project. Yet the very identification of such matters could be useful for researchers and decision makers involved in efforts to work together on food intake and food choice motives.

Together the project partners have managed to achieve better insights into a field of research that is gaining importance in our modern society. The matter of how to do this will depend on the rapid development of information technology and also possible changing legal conditions. But the issues found and described here in this report will be relevant in the future as well.

The project is financed by the partners and the former Netherlands Ministry of Economic Affairs (now the Ministry of Agriculture, Nature and Food Quality) through the Dutch Top Sector (TKI Agri& Food).



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Summary

Smart Food Intake is a project to improve the collection of reliable, accessible and up-to-date food intake data and underlying food choice motives as important determinants of food intake. A flexible, modular system based on the 2-hour recall ('snapshot') methodology was developed to reach that aim. This methodology will enable the food industry as well as the research community to collect data on food intake in a faster, flexible and more reliable way.

The project was a precompetitive public-private collaboration on methodology development among the food industry and WUR. Most effort was put into the work on the tool (i.e. the methodology and SFI-Traqq app). The design of the methodology has now (largely) been published and is as such public and a video has also been published (Lucassen et al. 2021).¹ Whereas the methodology was the main product promised in the plan for SFI, the SFI-Traqq app itself was not planned upfront. It emerged as an option during the project and to work it out was a joint decision by the project team. Eventually the tool should help researchers and industry to faster and cheaper collect necessary insights that can be used to develop food products and interventions that better fit the needs of a diverse range of consumers and lead to an on average higher intake of healthy foods. During the project we also concluded that collaboration on data management, such as sharing data, is hard due to a demanding EU regulation (GDPR). The need to comply to the FAIR principles (Findable, Accessible, Interoperable, Reusable) is now strong. Sustained attention to issues like the need for new types of consent agreements and collaboration within a broader platform (such as FNH-RI) are also necessary.

We conclude that joint work on tools, data and services for food intake and food choice motives is useful but it demands clear ownership and rigorous governance rules. Legal demands are essential and must be included from the start of a study. There is a need for more joint experiences and more established modes of working together on tools, data and services. Future challenges include the improvement of the awareness of and willingness to work for and actually reach new modes of joint working on tools for food intake and food choice motives.

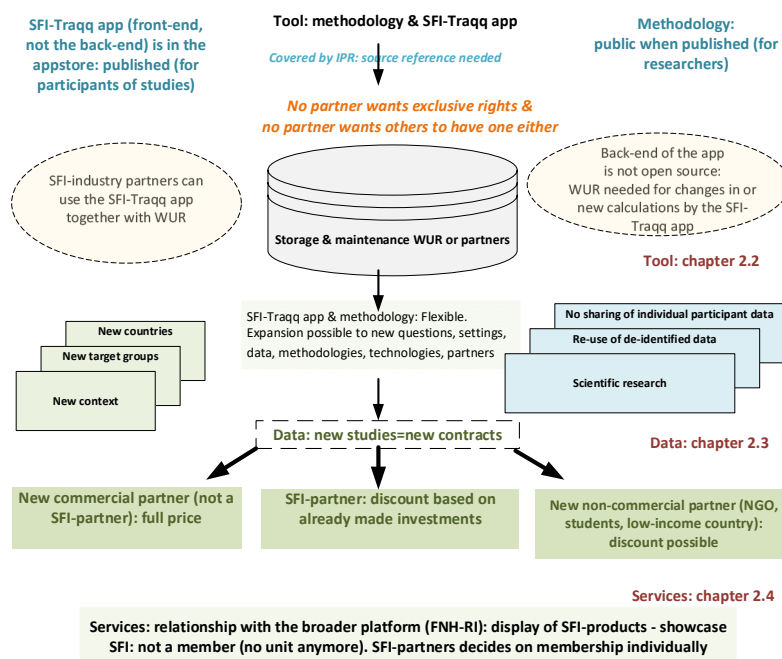


Figure S.1 After the project: Guidelines for conduct of Smart Food Intake products
Source: this project.

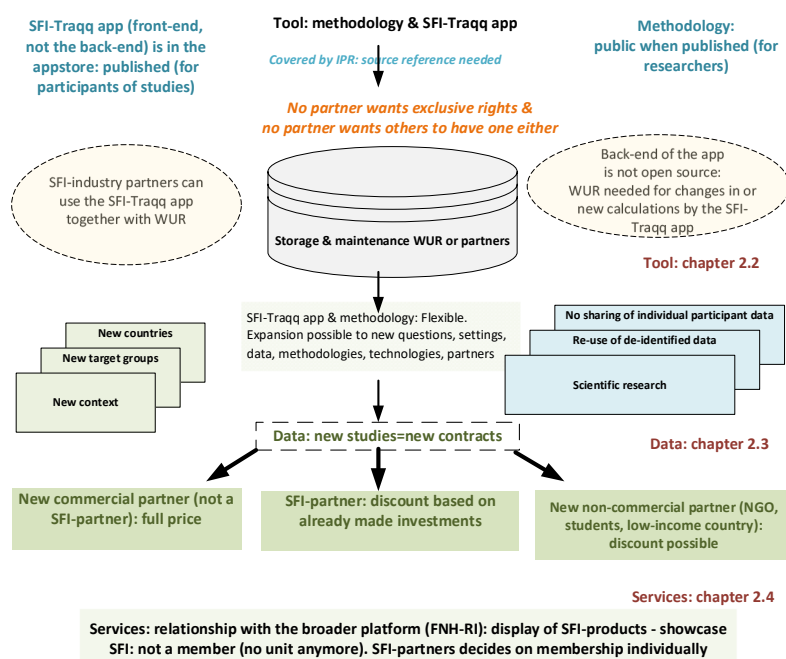
¹ <https://www.jove.com/v/62032/iterative-development-an-innovative-smartphone-based-dietary>

Samenvatting

Smart Food Intake is een project gericht op het verbeteren van het verzamelen van betrouwbare, toegankelijke en up-to-date data voor de inname van voedsel en de onderliggende motieven voor voedselkeuzes als belangrijke determinanten van voedselinname. Om dat doel te bereiken werd een flexibel, modulair systeem ontwikkeld op basis van de 2-uurs recall-methode ('snapshot'). Deze methodologie stelt zowel de voedingsindustrie als de onderzoeksgemeenschap in staat om sneller, flexibeler en betrouwbaarder gegevens over voedselinname te verzamelen.

Het project was een pre-competitieve publiek-private samenwerking voor de ontwikkeling van een methodologie door de voedselindustrie en WUR. Het meeste werk zat in de tool (i.e. de methodologie en de SFI-Traqq app). Het design van de methodologie is (grotendeels) gepubliceerd en dus openbaar en er is ook een video gepubliceerd (Lucassen et al. 2021). De methodologie was het belangrijkste product beloofd in het plan voor SFI, maar de SFI-Traqq-app was niet van tevoren gepland. Het idee voor een app ontwikkelde zich tijdens het project en het werken hieraan was een gezamenlijk besluit van het projectteam. De tool zal researchers en industrie helpen om sneller en goedkoper inzichten op te bouwen voor de ontwikkeling van nieuwe voedselproducten en interventies die beter aansluiten op de behoeften van de diversiteit van consumenten en leiden tot een gemiddeld hogere inname van gezonde producten. Tijdens het project concludeerden we dat samenwerking op het gebied van datamanagement, zoals het delen van data, lastig is vanwege de veeleisende EU-regulering (GDPR). De behoefte om te voldoen aan de FAIR-principes (Findable, Accessible, Interoperable, Reusable) is nu sterk. Een duurzaam aandacht voor dit soort vraagstukken vraagt ook werk aan zaken als nieuwe vormen van consent-afspraken en ook samenwerking binnen een breder platform (zoals bijvoorbeeld FNH-RI).

We concluderen dat het gezamenlijk werken aan tools, data en services voor voedselinname en motieven voor voedselkeuzes nuttig is, maar dat het ook belangrijk is om een helder beeld te krijgen van wie de eigenaar is, met duidelijke governance-regels voor het gebruik. De juridische eisen zijn essentieel en ze moeten vanaf het begin van een studie meegenomen worden. Er is wel behoefte aan het opbouwen van meer gezamenlijke ervaringen en werkwijzen als het gaat om het werken aan tools, data en services. Uitdagingen voor de toekomst omvatten het versterken van het bewustzijn en bereidheid om te werken aan en ook het daadwerkelijk ontwikkelen van nieuwe manieren van samenwerken aan tools voor voedselinname en motieven voor voedselkeuzes.



Figuur S.1 Na het project: Guidelines voor de omgang met Smart Food Intake-products

Bron: dit project.

1 Introducing Smart Food Intake

1.1 Improving the understanding of food behaviour

The project Smart Food Intake (SFI, 2017-2021) originates from the need to stimulate more healthy and sustainable food consumption, with better insight into the what, where, when and why of food consumption. In the plan (SFI Consortium Agreement and plan proposal, 2017) the background and aim are described:

'The food industry has indicated the need for more advanced data collections methods for food intake and its determinants, to better collect the necessary insights. With these insights, food formulations, communication and interventions can be tailored towards various target groups better than before. Current methods on food intake and food choice motives come with a range of drawbacks, including:

- a lack of linkage between food intake and its determinants,
- a lack of inclusion of contextual variability,
- high measurement errors,
- time-consuming data collection and
- a high burden for the consumer and the researcher.

Therefore, the aim of SMART FOOD INTAKE is to improve the collection of reliable, accessible and up-to date food intake data and underlying food choice motives as important determinants of food intake. A flexible, modular system based on the 2-hour recall ('snapshot') methodology will be developed to reach that aim. This methodology will enable the food industry as well as the research community to collect data on food intake in a faster, flexible and in a more reliable way.'

The project SFI:

- is a precompetitive public-private collaboration on methodology development where the industry and knowledge institutes engage in co-creating a flexible, modular 2-hour recall (snapshot) methodology;
- partners in this collaboration are the knowledge institutes Wageningen Economic Research (project lead) and Wageningen University, Division of Human Nutrition and Health (WU-HNH), with four private parties: Danone, FrieslandCampina, Philips and Unilever Foods Innovation Centre Wageningen;
- is co-financed by the former Netherlands Ministry of Economic Affairs (now the Ministry of Agriculture, Nature and Food Quality) through the national Top Sector (TKI Agri& Food).

The methodology was the core focus promised in the Consortium Agreement and during the project an app was developed for testing the methodology. This SFI-Traqq app is no official deliverable of the project SFI but together with the methodology the app forms what we here call the tool of SFI.

The project is related to previous projects (i.e. EuroDish, DISH-RI, ENPADASI, RICHFIELDS) that led up to developing a new platform, now called Food, Nutrition and Health-Research Infrastructure (FNH-RI; <https://fnhri.eu>) for more harmonisation of data collection methods and less fragmentation of data collection and usage.² SFI developed a methodology for more harmonised and standardised ways of collecting and analysing data, and as such is could be one of the building blocks for the FNH-RI platform. The core of SFI has been the methodology, but we also focused on data (sharing) management, and services.

1.2 Aim and research question

The aim of this report is to present the guidelines for conduct after the project. To achieve this aim we need to relate the guidelines to challenges such as the scientific FAIR principles for data management and legal

² https://www.researchgate.net/figure/DISH-RI-situated-in-the-European-research-landscape-As-an-overarching-RI-unique-for-the_fig1_322215110

issues concerning the protection of data (General Data Protection Regulation GDPR) and possible future services offered through a partnership such as the FNH-RI.

The main research question is then: which governance guidelines do we have for after the project? For an answer we describe the guidelines for the tool made in the project (i.e. the methodology and the SFI-Traqq app) and the data management and possible services for after SFI.

We will then link these guidelines to the scientific FAIR principles and the legal context of GDPR because these will have effects on how to deal with the tool, data and service after the project.

The possible link to FNH-RI is not decided upon within SFI: it is here meant as a way forward for more lasting effects of the results, in a broader setting where further collaboration is made possible. The FNH-RI is itself in the stage of being built up, thus our possible linkages between SFI and FNH-RI are tentative. We also offer reflections from the project on why collaboration on data sharing is so desirable but yet so hard to achieve.

The main audience for this document is the research community working on or interested in how to achieve more collaboration on the development of tools, data and services for a better understanding of food behaviour. The report might also be relevant for decision makers active on these matters within both public and private organisations.

1.3 Method of work

The work was based on qualitative methods consisting of the following parts:

- a. a literature/document study was conducted on data privacy, data management, the FAIR principles of scientific research and legal demands (GDPR) and Research Infrastructures. The result was insights into what the FAIR principles mean for SFI; it helped to identify important barriers (i.e. legal constraints of the GDPR) and opportunities (i.e. input on what RIs are and how they might play a role in future collaboration);
- b. interviews/meetings with experts (coordinator of FNH-RI, the scientific leader of ENPADASI and a legal officer of WUR). This resulted in insights from the actual efforts experienced within FNH-RI on future collaboration; from ENPADASI on data sharing and from the legal officer of WUR on possible sensitive legal matters); and
- c. interaction within the project team (e.g. workshops, project meetings, one-on-one consultations, text reviews). This resulted in a process of developing a joint understanding of the work being conducted on the methodology, app, data and future collaboration. This interaction of the partners also helped to clarify further how to deal with sensitive matters.

1.4 Guide to the reader

Chapter 2 offers guidelines for conduct after the SFI project ends. First, we offer an overview in a figure containing the most important guidelines (Section 2.1). Then we present the guidelines for the use of the tool, which is here seen as the methodology and the SFI-Traqq app (Section 2.2). We continue by looking closer at the data sharing guidelines after SFI (Section 2.3). In this section we first offer a view to data sharing after SFI (Section 2.3.1), then we present the data policy at WUR (Section 2.3.2), before we present a link to the FAIR principles (Section 2.3.3) and the legal demands from GDPR (Section 2.3.4). Then, in an intermezzo, we offer a comparison and lessons from a project focusing explicitly on data sharing, ENPADASI. In the subsequent part we present ways to offer services to the upcoming European platform FNH-RI (Section 2.4). In a second intermezzo we propose a view to a future project with a more complex setting outside the EU, to highlight some of the choices that have to be made in research to come. Chapter 3 contains a reflection on why collaboration is as attractive as it seems but yet so hard to actually achieve. The need for such a reflection came up during our meetings and it is meant for a further understanding of the conditions for collaboration on methodology but in particular data management. Chapter 4 contains the main conclusions, with future challenges for enabling a continuation of the collaboration.

2 Guidelines for conduct after SFI

2.1 Overview of guidelines

Figure 2.1 shows an overview of guidelines for conduct after SFI. The products of SFI referred to here are the tool (i.e. methodology and SFI-Traqq app), data and studies (i.e. articles, deliverables). From the top we specify the use of the tool with the SFI-Traqq app (front-end left and back-end right) and that no partner would like an exclusive right to the tool, and that they do not want others to have it either. In the middle we make clear what you can do with the tool in research, also if one wants to engage in new studies after SFI. At the bottom of the figure there is a reference to a possible link to a future platform for further research after SFI. More details follow in the subsequent sections.

We add here that the figure can be seen as process flow chart. From above there is first the tool (i.e. methodology and SFI-Traqq app) and the guidelines to deal with the tool (more in Section 2.2). Then a lower part covers rules for data management (Section 2.3). The bottom part contains a view to opportunities for new studies (Section 2.4).

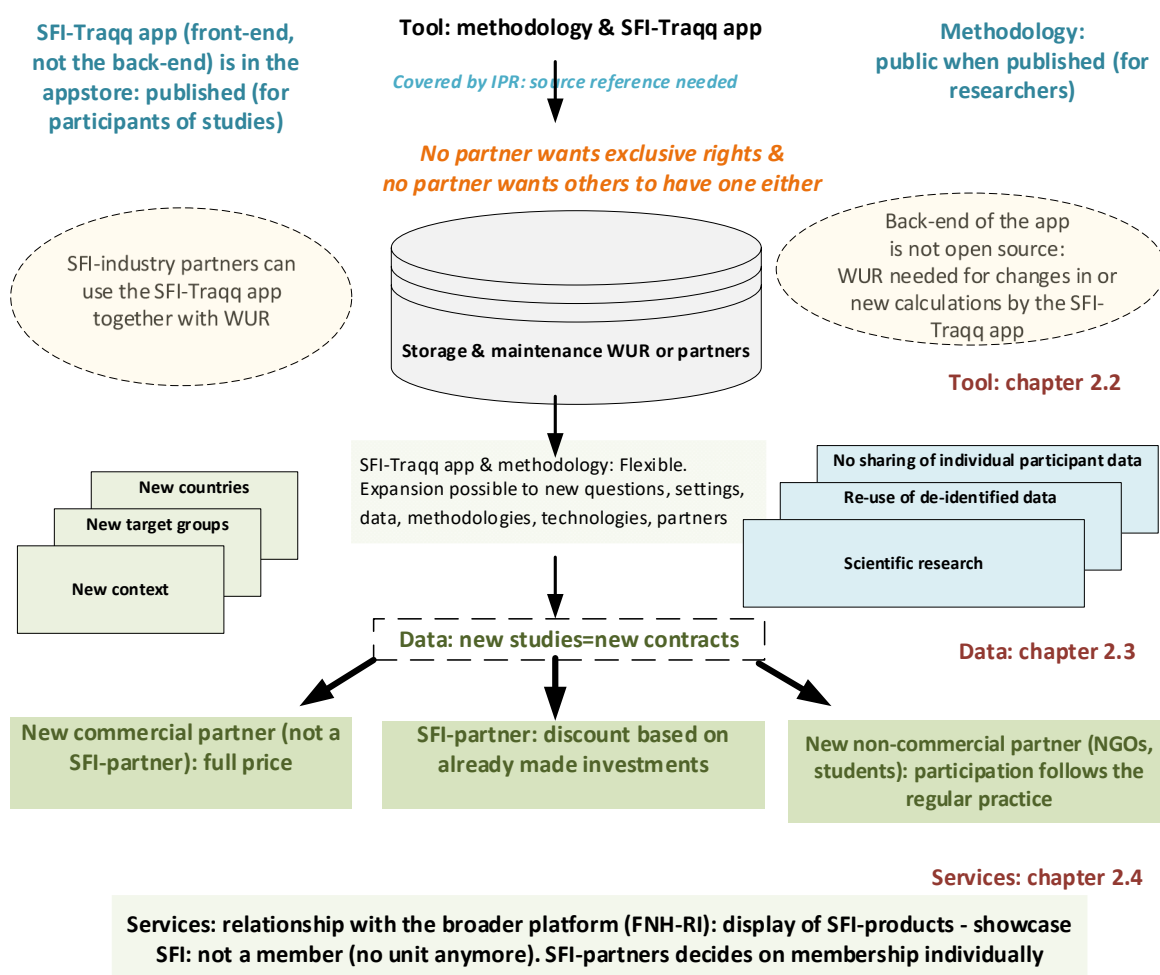


Figure 2.1 After the project: guidelines for conduct of the Smart Food Intake products

2.2 Tool: the methodology and the SFI-Traqq app

The core of the SFI project comprised the joint work on a methodology to improve our understanding of food intake and food choice motives. As the prime concern, this work called for intensive efforts to achieve or enhance a joint understanding of how to interpret words/concepts used, such as data, meta-data and data storage. The reason is simply that people, coming from a variety of backgrounds and settings, tend to define and use the language involved in different ways. But it is necessary to arrive to joint interpretations when it comes to matters like harmonisation and standardisation of the methodology. This part resulted in the integrated, flexible, modular 2-hour recall (snapshot) methodology to measure food intake and food choice motives across eating contexts.

The upper part of the figure shows the tool (i.e. the methodology and app). The design of the methodology has now been published and is as such public and also a video has been published (Lucassen et al. 2021).³ Whereas the methodology was the main product promised in the plan for SFI, the SFI-Traqq app itself was not planned upfront. It emerged as an option during the project and to work it out was a joint decision by the project team. The inspirational source of this option was the FoodProfiler and the Food Intake App, which WUR already had made before and/or in parallel with SFI. For the execution of the SFI project the partners had access rights to all parts involved. But these existing parts were excluded from SFI to prevent confusion and new discussions on access rights as these discussions have been closed with the signing of the contract. Wageningen Economic Research could use its own FoodProfiler to perform its tasks, and WU-HNH could use its Traqq-app). The Food Intake App was then adjusted to the purpose and needs of SFI, and this we now call the SFI-Traqq App, owned by WUR. During SFI this tool served to develop, apply and evaluate the methodology.

In principle, no explicit decisions on storage and maintenance have been made during the project. This will depend on how useful it is regarded to keep the app and its back-end going. It is now stored at a WUR server. The SFI-Traqq app is now in the Appstore, which means the front-end of the app is published. The front-end is however mainly meant for the participants of a study (see the top left and right of the figure), or it can be used for instance as a diary. It is not possible to just download the app making changes or conducting a new study. In general the partners may use the joint results of SFI for their own internal research purposes for 6 months after the end of the project (31-12-2021), royalty-free and without any prior consent of the others involved. During this period the parties shall decide on whether or not they want an exclusive licence regarding the SFI results. But the partners have made it clear that no partner wants exclusive rights and that no partner wants others to have an exclusive right (licence) either.

The tool can be used to develop new studies (see the middle, lower part of the figure), with new research questions and the collection of new data. The app itself is not for making further nutritional calculations. For this work there is other software programs available at WUR. The argument that the app should be open to all for free usage also came up in discussions during the project. But however preferable it could seem, the overall conclusion is that it will not be Open Source. The reason is that there is know-how involved, it is part of the business model, for initiating new studies and collecting the data. There is also the argument that a free usage, without any (scientific) quality control, could jeopardise the reputation of the tool. For future usage of the tool the SFI partners will have a discount for already made investments in the project while external (commercial companies) pay full price, which is a price that includes already made development costs and maintenance costs etc.

The most important aspect is that the methodology and the SFI-Traqq app are flexible tools and expansion to new questions, contexts, targets, countries is possible. It could for instance be that the SFI-Traqq app needs to be translated to another food database, or into another language and cultural context (see intermezzo 2). In Section 2.4 we also link SFI to the possibility of future collaboration within a platform like FNH-RI.

³ <https://www.love.com/v/62032/iterative-development-an-innovative-smartphone-based-dietary>

2.3 Data: data sharing guidelines after SFI

2.3.1 Data sharing after SFI

Data sharing after SFI is based on the protection of participant privacy and reducing the risk of data misuse. Data sharing will then be restricted to de-identified data, i.e. data that cannot be traced back to individuals. The granting of access to (these de-identified) data will be decided upon by the data controllers and processors in question. These must then take the GDPR regulation into account when making the decision of using data, and the data policy of the organisations involved. From a privacy perspective, GDPR clearly states that collecting information about individuals should be minimised to the amount that is needed to achieve the purpose of the data collection – and not more. In addition to that, it can complicate de-identification of data sets if much information about a person has been collected. The more information that is collected about a person (e.g. in an extensive survey, collecting information about the person's demographics, background, storing of IP address, etc.) the harder it will be to prevent that it becomes possible to link survey data to the identity of that person. The SFI partners are however hesitant to open access to data not only due to GDPR. Open access to data is also considered problematic due to the value the collected data represent. There are costs involved in the collection of those data sets, and in some cases also confidentiality for business purposes play a role. Within SFI, explicit plans for data sharing after the project were not made as it was never part of the project. However, the current data policies of the SFI partners ensure a rigorous data governance and a regulated access to data and data management tools on a case-by-case decision of the data controller and processor. De-identified or anonymised data could be subject to sharing but there are no specific provisions for this made in the project.

During the project the collection of data through the SFI-Traqq app went rather smoothly but efforts to actually share additional data became difficult. For research such a sharing could have been interesting but in practice it often turned out to be difficult due to the strict regulations of GDPR.

2.3.2 As open as possible, as closed as needed: SFI and data sharing@WUR

We emphasise that much of the work on mutual insights is based on collaboration. But much of the data collected through the SFI-Traqq app are further processed and stored at the servers of WUR, the knowledge partner in this project. As such, the WUR data policy is of relevance. Depending on the type of data and data ownership, there might be a restricted access to the data through a contract with WUR. Any of the personal data collected by WUR through the SFI-Traqq app are subject to a closed access. Any joint future data sharing calls for an agreement on sharing anonymised or de-identified data in compliance with the GDPR. When it comes to the data policy of WUR, the motto for data sharing at WUR is *as open as possible, as closed as needed*. But the openness will be subject to a rigorous data check, including a strict scrutiny of the consent involved. Data traceable to natural persons will not be shared. The figure below illustrates the policy at WUR.

Data sharing @WUR: as open as possible, as closed as needed



Figure 2.2 Data sharing @WUR

Published data are by definition open access. But both open data and data with a restricted access are supported by WUR through recognised systems as 4TU ResearchData, DANS and Zenodo (see Table 2.1). These systems help WUR to comply with high standards of data management.

Table 2.1 Data repository initiatives

4TU.ResearchData is an international data repository (federation) for science, engineering and design, offering research dataset curation, sharing, long-term access and preservation services to anyone, anywhere: raw, edited or published data can all be uploaded. With training and community engagement resources for research support make data findable, accessible, interoperable and reproducible (FAIR).

DANS is the Dutch national centre of expertise and repository for research data owned by the national Academy of Science KNAW and the Research Council NWO, with about 180,000 datasets. It helps researchers make their data available for reuse and allows researchers to use the data for new research and makes published research verifiable and reproducible. <https://dans.knaw.nl/en>

Zenodo helps researchers receive credit by making the research results citable and through OpenAIRE integrates them into existing reporting lines to funding agencies like the European Commission. Citation information is also passed to DataCite and onto the scholarly aggregators. The code is itself open source, and is built on the foundation of the Invenio digital library which is also open source. The work-in-progress, open issues, and roadmap are shared openly in GitHub, and contributions to any aspect are welcomed from anyone. All meta data are openly available under CC0 licence, and all open content is openly accessible through open APIs. <https://zenodo.org/>

2.3.3 FAIR for the future

The FAIR principles for data management in scientific research are mentioned above and these are important to all current and future work. FAIR refers to data being Findable, Accessible, Interoperable and Reusable (see Appendix 4). These are not legal requirements. They are scientific principles that serve to guide data producers and publishers to knowledge discovery and innovation (Wilkinson et al. (2016:1)). The principles apply not only to 'data' in the conventional sense, but also to the algorithms, tools, and workflows that led to that data. All scholarly work, from data to analytical pipelines, benefit from the application of these principles, since all components of the research process must be available to ensure transparency, reproducibility, and reusability (Wilkinson et al. 2016:1). The FAIR principles are increasingly becoming a part of practice for (academic) researchers. In the Dutch practice the principles are now propagated by research funders such as the national research council NWO, the national Academy of Science KNAW and public organisations such as the Ministry of Agriculture, Nature and Food Quality, the Topsector Policy TKI (which is co-funding SFI) and the health research funder ZonMW. But also the EU increasingly propagates the FAIR principles.

For the situation after SFI no specific agreements have been made by the SFI partners. We suggest the relevance of the use of 4TU.ResearchData, DANS and Zenodo. These are examples of means, used for instance by WUR, that ensure that all data are FAIR-proof. Within SFI, WUR also used the Dutch Food Composition Database (NEVO) coding, which contains data on the composition of foods eaten frequently by a large part of the Dutch population. NEVO is published by RIVM, the National Institute for Public Health and the Environment.⁴ The version used for SFI has however been adjusted by WUR for this purpose and this version must then be kept FAIR by WUR.

2.3.4 Legal demands: GDPR

For the legal protection of data the General Data Protection Regulation (GDPR) is of great importance. GDPR came into force during the project in May 2018 and presents strict rules for data protection in the EU. Its focus is that individuals have more control over their personal data and businesses benefit from a level playing field. The aim is to protect EU citizens from privacy and data breaches in an increasingly data-driven world that is vastly different from the time in which the 1995 directive about data protection was established. The GDPR replaced the Data Protection Directive 95/46/EC and was designed to harmonise data privacy laws across Europe, and empower all EU citizens data privacy and to reshape the approach to data privacy. GDPR also applies for companies and research in other parts of the world if it involve EU-citizen data. It does not apply if you are operating in, say, the US or China, and not transferring data for e.g. processing in the EU. The GDPR has however a long reach and the picture might be a bit more complex, but in essence it is about protecting EU citizens, thus any specific usage/processing of data outside the EU should be carefully checked.⁵ For research there are some special provisions. Saving personal data longer than the purpose of processing might be allowed in the public interest, or for scientific, statistical or historical research. There could be tension between the GDPRs direction to delete personal data once it does not serve any purpose and the need to archiving data for at least ten years for the reasons of scientific integrity. To avoid tension one must de-identify/anonymise the personal data when possible. Anonymisation means that it is not possible to link the data to a person, there is no key anymore. For future research archiving personal data for assessing scientific integrity must be described right from the project proposal and the informed consent procedure, then the data subjects are informed. But again a careful case by case check is necessary.⁶ For future data management the 'right to be forgotten' also might play a role. This is a special case of 'the right to be informed', under Articles 13 and 14 of GDPR, which provides the consumer access to his or her own data, making data storage, sharing and using even more FAIR.

Intermezzo 1: SFI meets ENPADASI on data sharing

Although SFI aimed to develop a joint methodology for collecting and analysing data, also sharing data was an issue of interest. As such SFI can learn from the project ENPADASI, which focused explicitly on data sharing. Both projects are rooted in great challenges of highly heterogeneous issues and a growing

⁴ <https://www.rivm.nl/en/dutch-food-composition-database/about-nevo-data>

⁵ <https://gdpr.eu/companies-outside-of-europe/>

⁶ <https://www.ru.nl/rdm/gdpr-research/faq-gdpr-research/#h73884adf-b9b0-4c21-84a0-60caa78c3a77>

recognition of the need for more integrated and interdisciplinary studies and to move away from fragmented approaches to dietary assessments (Ludwig et al. 2019). Data sharing is then part of the challenge. The European Nutritional Phenotype Assessment and Data Sharing Initiative (ENPADASI)⁷ was a project that aimed to deliver an open access research infrastructure that will contain data from a wide variety of nutritional studies, ranging from mechanistic/interventions to epidemiological studies including a multitude of phenotypic outcomes that will facilitate combined analyses in the future (see Appendix 6 for a list of the ENPADASI principles).

The ENPADASI principles express an ambition for making data accessible, already from the early stages of a project. It also advocates a stronger focus on making data available for sharing, and that data should be prepared for that purpose, with a de-identification of data, where any citizen or group with a reasonable scientific question and the expertise should be able to request access to individual participant data and trial documents. But ENPADASI (see Bouwman et al. 2015 , deliverable 1.2.1.) also observed that sharing for ethical and/or legal issues can be restricted. The only actual sharing within the project concerned meta-data (data about data), no actual data were revealed. Consequently, the nutritional community at least became aware of the existence of the dataset. It is emphasised that any actual sharing of data between specific partners calls for a DTA (data transfer agreement), and a data access committee to prevent potential sharing difficulties and to check regulatory compliance. Also, future data collections with the SFI-Traqq app will require a DTA but no agreements have been made yet, because such an agreement is only relevant when a specific new data collection will be made.

ENPADASI is also a pledge for an explicit broad consent for individual participant data sharing and reuse of data for scientific purposes. Broad consent is in general seen as gaining one consent for reuse in future research, an effort that is not applauded by EU regulators. Also for ENPADASI this is an ambition one just cannot apply in general terms. Broad consent requires, by GDPR, a specification of the type of research which will be conducted with the data and it requires pseudonymisation and adequate data protection. The scientific community in general is now working on this issue in discussions with policy makers, as it is of great interest and concern. Future research might benefit from new types of consent, such as Dynamic Consent, which is an approach to consent that enables people, through an interactive digital interface, to make ongoing decisions on participation (Pictor et al. 2020). But business/research organisations and data protection authorities are currently strict on this one.

We might add here that ENPADASI never actually shared any personal data, just as SFI. We use this project as an example because of its focus on data sharing, not because ENPADASI actually shared personal data. The only sharing possible for both ENPADASI and SFI concerns de-identified data where anonymity and privacy of the participants are ensured. Within SFI there have been discussions on this where researchers often express a need for data sharing for scientific purposes. But we realised that this need covers more than just sharing datasets. During the project we came to recognise that building up a reservoir of joint understanding among different disciplines and types of researchers from both public (the university) and private (businesses) is a key to future research. Any actual sharing of data might then evolve as a result of joint efforts, if and when such plans for data sharing after the project have been developed and become trusted and therefore also legally accepted. But this was not the situation during SFI.

ENPADASI also emphasise the need to support and maintain the data infrastructure for the long term. However, as the ENPADASI deliverable 1.2.1 says, the maintenance of the system was not taken care of during the project. This point is similar to SFI, although the maintenance can be taken care of by WUR.

In sum the main lesson learnt from ENPADASI is that data sharing must be part of a study from the beginning, based on a rigorous data governance with strict data sharing rules to prevent difficulties and a consent form that allows data sharing and re-use of data. SFI was however not really designed for data sharing and due to the rigid EU rules of GDPR one must be cautious and remove information that would allow the identification of individuals. For future research we can state that data sharing will call for more attention to new ways of approaching consent but also comprehensive systems of data management based on the FAIR principles.

⁷ The ENPADASI is a multidisciplinary consortium of scientists from 50 research centres in 9 countries across Europe set up for sharing each other's studies, including the data. <http://www.ENPADASI.eu/>

2.4 Services: SFI and the upcoming European FNH-RI platform

For SFI the upcoming European FNH-RI platform FNH-RI for Food, Nutrition and Health is one of the opportunities to proceed further. Already from the beginning of SFI the affiliation with FNH-RI was present, although FNH-RI was in a stage of being built-up. For the future it could serve as a place to make the methodology and the app more visible and enhance the connectedness to the research community. The reason is that FNH-RI already is connecting more than 150 institutes from 24 countries, with researchers, citizens, data scientists, industry and technology developers to boost research on eating patterns (see <https://fnhri.eu/>). FNH-RI offers standards and procedures for data sharing, and harmonised protocols for tools, facilities and training, aiming to link consumers, preventive health care and the food system by better research tools, data and services. The SFI tool (methodology and app) could then be part of this upcoming research community based platform. However, no decision has been made on whether and how SFI will be linked to such a larger platform for future research like FNH-RI. We add here that the SFI tool can be used without any link to such a platform. But if such a link is made, SFI can in fact be attached to the FNH-RI in various ways. We see at least five ways to do so:

1. display the SFI tool (methodology/SFI-Traqq app) and meta-data for further usage and development;
2. offer a link to the tool (methodology and SFI-Traqq app), with guidance/trainings (services) for how to use it in collaboration with WUR;
3. the SFI partners can decide to act as a group in a continued type of new joint engagement (such as a new project);
4. the SFI partners can become members separately;
5. FNH-RI can finance parts of the maintenance of SFI-related subparts in a more formalised data collaboration.

The background for the concept of Research Infrastructures (RI) is briefly introduced in the textbox.

RI are facilities, resources or services for research (European Union, 2011). In the EU, the notion of RI has been a strategic instrument since 2002. The main part of the policy is called the ESFRI, which is the European Strategy Forum on Research Infrastructures, initiated by the Member States and the European Commission to develop the scientific integration of Europe and to strengthen its international outreach (European Union, 2011:7). There are RIs on most scientific fields and they can be single-sited (a single resource at a single location); virtual (the service is provided electronically) or as in the case FNH-RI, distributed (a network of distributed resources).

The option of continuing the collaboration after the project SFI was discussed during the project. In general the project SFI is then finished, and consequently the collaboration is formally ended. The SFI partnership is then no longer existing and SFI as such cannot become member in any way, as it is no unit anymore. The SFI-partners decides on membership individually. However, the SFI partners can very well choose to continue together with a new contract of collaboration or as an informal loosely connected 'unit', just based on interest and trust with no strings attached. One of the concrete options to link the SFI tool (methodology and app) to FNH-RI could be through the FNH-RI project COMFOCUS and its development of the Easy Questionnaire Service. In that way insights from SFI could become more and better integrated into FNH-RI.

Intermezzo 2: a business model for an imaginary study in Nigeria in French after SFI

For offering some clarification of the future situation we present an example of an imaginary study. But now the setting is new: it takes place in Nigeria and the language is French. In this way, we introduce extra complexities since data collection is happening in a different country, outside the EU.

In this hypothetical case, one industry SFI partner starts a new project together with another commercial business company and an NGO, none of them ever involved in SFI. The setting is Nigeria. The initiator(s) of the study might then engage with WUR for applying or making further adjustments to the app. WUR does not necessarily need to be much involved in the actual (local) project work. But the tool is usable for such a new

partnership can search for new insights in a new context, to enable an expansion of the joint insights into food intake and food choice motives. The industry partners of SFI would then do not have to pay for already made investments. An NGO might have a discount by WUR, depending on how WUR assesses the need involved (i.e. educative, social, societal needs) and the NGO's financial resources. But any new commercial industry partner pays the full price. This would be integrated into the research plan agreement. It is then of importance to consider whether the data somehow are going to include EU-citizen data, by for instance conducting a comparison. As the GDPR is made to protect EU citizens the law applies to organisations that handle EU-citizen data whether they are EU-based organisations or not, known as the 'extra-territorial effect'.⁸ In every specific case the organisation involved should seek legal aid to determine the application of GDPR, in addition to the national data protection rules of Nigeria.

The further costs of the project depend on the adjustments of the app and/or methodology. The Nigerian food composition will have its own specific features and there will be work needed to adjust to this specific setting.

In principle, in new research projects all types of changes are possible. For WUR there could be scientific or educative reasons to be involved, and possibly also goodwill elements. But overall the essence is that the SFI tool is being used to analyse new types of data in a new context. And just like any other project, already from the stage of a proposal the FAIR principles will apply fully.

⁸ <https://gdpr.eu/companies-outside-of-europe/>

3 Why collaboration is so attractive but yet so hard

Collaboration on the development of a joint methodology and engaging in data sharing are attractive ways of working for researchers seeing the advantages of collaboration on data sharing and joint analysis of data, appreciating the added value of SFI regarding such collaboration. Individual researchers within SFI have acknowledged the need to engage in joint analysis of food behaviour, as this broadens up views and also leads to new insights. The project SFI was also seen as a new type of working: a novelty that inspired to collaborate on a new methodology, although collaboration as such is not so new. The researchers also embraced the thinking behind Research Infrastructures, which is founded on such collaboration.

At the same time it is very hard to actually engage in data sharing collaboration due to strict policies (i.e. standards and terms) on data protection from the different organisations following the GDPR. Researchers must always work closely together with their legal department to meet the standards required, whether it concerns global standards or national laws. The reasons why it is often quite hard to share data collected by one partner with another partner are however manifold, and GDPR is one of the essential reasons. It is also hard to ensure that data actually can be shared with the other party. The participants in the original data collection would then have to be informed about who would be given access to the collected data, and also which part of the data set it would comprise. Besides, to further comply with GDPR, it is vital that data sets are 'cleaned' to ensure that the partner who will receive the data set is getting only those parts of the data set that are relevant for their purpose - which can mean that particular items may need to be stripped from original data set, before the data are shared; and legal departments must then also verify this. What legal departments of companies also want to verify is that the rights to any new products, services, IPR, etc. that might result from the processing of the (stripped) data set are clearly described: who will have those rights, and what does that mean for the data-sharing agreement. All data handling organisations then became cautious due to the fear of harsh fines against those who violate its privacy and security standards.

During the project we concluded that the collaboration we engaged in during SFI might not be new in all aspects but that it is also not a very common way of working and in combination with the legal concerns (GDPR) there are strong incentives for being cautious about the conditions for collaborating. Evidence from other sources confirms the observations above. We saw it in the systematic review on barriers to data sharing in public health conducted by Van Panhuis et al. (2014), and also their argument is that the benefits of data sharing are widely recognised, but in reality it can be very challenging. Van Panhuis et al. (2014:5) argue that organisations tend to be very restrictive when it comes to data and inclined to be guardians of privacy rather than data sharing. The protective ownership role might then prevail for fear of a lack of properly data protection. We also saw this from the project Richfields (Timotijevic et al 2021), the work on FNH-RI, talks with the scientific coordinator of the project ENPADASI, and we concluded the same from the 13th European Nutrition Conference (FENS) in Dublin from 15 to 18 October 2019 where we presented a scientific poster about SFI. During FENS, Joao Breda from WHO said that nutrition today is mostly about one's own lab work and diets. Establishing partnerships is crucial and that stronger collaboration eventually means better health. But he added that today there is too much silo thinking and short-term agendas regarding the governance of data and joint data work. He sees a time now for more implementation and practice, as dietary assessments call for innovative intake efforts. During our SFI poster presentation people from various countries, such as the USA, the UK, Ireland, Finland and the Netherlands, underlined the importance of data sharing for the future but also argued that what we do is not commonplace and that it is also hard to obtain funding for sustained research based on collaboration despite the need to do so.

4 Conclusion

The core of the SFI project comprised the joint work on a methodology to improve our understanding of food behaviour. Achieving a joint understanding and a joint tool based on harmonisation and standardisation of the methodology attracted enthusiasm and resulted in the integrated, flexible, modular 2-hour recall snapshot methodology to measure food intake and food choice motives across contexts, the main joint result of all the SFI partners. The SFI-Traqq app can now be used further by the SFI partners, with a licence from WUR.

Joint work on tools, data and services for food intake and food choice motives is useful but demands clear ownership and rigorous governance rules

We have achieved much in gaining understanding of the governance of data and methodology concerning food behaviour through collaboration among public-private organisations. We found a profound acknowledgment of the usefulness of joint methodologies and better and more data sharing among the SFI researchers from both the businesses and the knowledge institute. But we conclude that such a joint work on tools, data and services for food intake and food choice motives is very useful although it demands clear ownership and rigorous governance rules in order to be possible.

Legal demands are essential and must be included from the start of a study

At the same time we conclude that actual collaboration on data sharing is hard due to strict data policies of the GDPR. Legal rules are demanding and essential and must be included from the beginning of projects. The latter is also important because the rules often seem unclear to the organisations involved, and they need to elaborate on the actual applications of the rules in their specific situation. SFI came into being in a period when conditions for data governance were changing rapidly due to the coming of GDPR shortly after the start of the project. This led all the organisations involved to become very much aware of the risks of not complying to the strict rules of collecting, recording, organising, structuring, storing, using and erasing data.

Need for more joint experiences and more established modes of working together on tools, data and services

Although collaboration is not a new practice there is a lack of established modes of working together on food intake and food choice motives tools, data and services. Within SFI the organisations engaged in new ways of dealing with data management, and we appreciated the emerging joint understanding but we also saw a need for more opportunities to use information technology, such as data warehousing, to improve tools for making/collecting, storing and retrieving data. Much of this work is now in a stage of build-up, such as at WUR, and was not readily available during SFI. We also see the coming of opportunities for collaboration, with for example the possible coming of a platform for collaboration called FNH-RI. Such a platform was not operational during the project, but it could possibly become part of the near future challenges. Related to the latter is also the fact that data are valuable and as such they are important parts of the business model of the organisations involved.

Future challenges: improve awareness, willingness and modes of joint working

The challenges of the future are 1) to improve the awareness of the usefulness of data and methodology sharing and collaboration on understanding context-specific food behaviour; 2) strengthening the willingness to actually engage in such collaboration; 3) help improving joint modes of working on tools/methodology and data sharing. Together we then might improve the possibilities and also the culture for collaboration, based on trust and commitment in situations with mixed interests; i.e. interests that are different but still can be aligned.

All these challenges call for a development which supports the further FAIRification of data, being compliant to the GDPR, with secure data handling and easily findable, accessible and removable (personal) data. Researchers advocating more joint research will need new ways of dealing with consent for sharing and reuse of data, such as the notion of Dynamic Consent. Making the value added of more joint research attractive is then a target for researchers and industry individuals. A Research Infrastructure such as FNH-RI could then offer a platform for such efforts, enabling greater collaboration, efficiency, harmonisation and transparency in research, which in turn benefits the consumer, industry and other stakeholders (Traka et al. 2020). As a consortium we realised that such efforts demand mutual understanding, trust and gains for sustained collaboration also after SFI.

Websites and literature

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Appendix 1 Key concepts from the Consortium Agreement

Table *Key concepts for the project laid down in the Consortium Agreement*

SFI concepts CA	Description
Background	Data held prior to the project. The Intellectual Property Rights (ownership) remains then with the Partner who brought it in.
Foreground	Results from the project. Includes copyright, design right, patent right etc: the Party or Parties carrying out the work hold(s) the rights to that Foreground.
Joint Foreground	Refers to joint work and those doing the work hold the position as the Entitled Party or Parties.
Protectable Foreground	Each party agrees to inform other parties for which intellectual property rights can be obtained.
Right of First Negotiation	The knowledge institutes grant each industrial partner a right for first negotiation for an exclusive licence regarding the knowledge institutes protectable or protected Own Foreground and Joint Foreground owned only by knowledge institutes within the industrial partner's field of use.
Non-protectable Foreground	Free rights to the usage/IPR.
Protected Foreground	The usage of this Foreground will be decided by the Project Committee.
Third party involvement	Existing agreements on rights and obligations remain unaffected.

Appendix 2 WUR Data sharing agreement

WUR uses this framework to create a Data Sharing agreement in projects where data from third parties are used for analysis and conclusion. All data delivering parties must be involved. If data from different parties will be used and mixed, include all parties involved in the agreement.

Topic	Specifically
Definitions	List definitions for all the terms used in the agreement
Period of agreement	How long will receiver be entitled to use the data?
Description of dataset	Description of data to be transferred: data type, size, format, etc.
Licence	Data provider grants data receiver a non-exclusive, non-transferable, terminable licence to access, copy and use the data. Additional possible conditions - No modification of data, no derivatives, named users/departments only, use restricted to the Purpose defined
Purpose of data sharing	How will receiver use the data? <ul style="list-style-type: none">• What studies will be performed, what questions asked, what are the expected outcomes?• Can receiver use the data to explore additional research question without the explicit consent of the data provider?
Constraints on data use data disclosure	List restrictions on how the data or data findings can be used. <ul style="list-style-type: none">• Must the data receiver document how the data is used?• Can the receiver share, publish or disseminate data findings without the explicit consent of the data provider?• Under what circumstances is data disclosure permitted?
Data confidentiality	Describe the processes the receiver must use to ensure data confidentiality. <ul style="list-style-type: none">• What safeguards are in place to protect sensitive data?• The receiver guarantees that the data will be safeguarded from misuse and unauthorised access or disclosure
Data security	Describe the methods and infrastructure the receiver must use to ensure data security. <ul style="list-style-type: none">• Where and how should hard copies of data be stored?• Where and how should digital copies of data be stored? E.g. data should not be stored on mobile devices or transferred unless encrypted.• What kind of password protection should be used? E. g 2fa• Who will have access to the data?• How will access be monitored?• What will happen to the data after the data sharing period has ended?
Methods of data sharing	Describe how and when data will be transferred from provider to receiver <ul style="list-style-type: none">• Which methods will be used to transfer the data?• How will a secure connection be guaranteed?• Will the data be encrypted before transferral?• When will data be transferred from provider to receiver?
Financial costs of data sharing	Describe the costs of data sharing. <ul style="list-style-type: none">• What are the costs of data sharing?• Will the costs be paid by the provider, the receiver or both?
Publications	Describe the conditions whereby the data receiver may publish works based on the transferred data, e.g. provision of copies, review period, consent, acknowledgement statements, etc.
Warranty and Indemnity	Disclaimer: no warranty or guarantee is provided i.r.t. data quality and completeness, fitness for purpose. Provider excludes liability for loss or damage the receiver suffers on account of the receiver's use of the Data. Indemnity describes the agreements made if legal claims are made against either party
Termination and Modification	Describes the conditions whereby the DSA can be terminated or modified. For which term will confidentiality or other obligations survive termination of the agreement? <ul style="list-style-type: none">• Once the right of use expires, what happens to the data that has been transferred? Will the data be returned or destroyed?
Applicable law and jurisdiction	

Appendix 3 GDPR

Table 2 *Trends in law (EU Special Eurobarometer 431 – data protection, June 2015)*

Trends in law- Citizens' rights:
A 'right to be forgotten' will help you manage data protection risks online. When you no longer want your data to be processed and there are no legitimate grounds for retaining it, the data will be deleted. The rules are about empowering individuals, not about erasing past events, re-writing history or restricting the freedom of the press.
Easier access to your own personal data.
A right to transfer personal data from one service provider to another.
When your consent is required, you must be asked to give it by means of a clear affirmative action.
More transparency about how your data is handled, with easy-to-understand information.
Businesses and organisations will need to inform you about data breaches that could adversely affect you without undue delay. They will also have to notify the relevant data protection supervisory authority.
Better enforcement of data protection rights through improved administrative and judicial remedies in cases of violations.
Increased responsibility and accountability for those processing personal data - through data protection risk assessments, data protection officers, and the principles of 'data protection by design' and 'data protection by default'.

EU Data protection principles	Outlined in GDPR Article 5.1-2: https://gdpr.eu/what-is-gdpr/
Lawfulness, fairness and transparency	Processing must be lawful, fair, and transparent to the data subject.
Purpose limitation	You must process data for the legitimate purposes specified explicitly to the data subject when you collected it.
Data minimisation	You should collect and process only as much data as absolutely necessary for the purposes specified.
Accuracy	You must keep personal data accurate and up to date.
Storage limitation	You may only store personally identifying data for as long as necessary for the specified purpose.
Integrity and confidentiality	Processing must be done in such a way as to ensure appropriate security, integrity, and confidentiality (e.g. by using encryption).
Accountability	The data controller is responsible for being able to demonstrate GDPR compliance with all of these principles.

Appendix 4 The FAIR principles

The FAIR Guiding Principles

To be **Findable**:

- F1. (meta)data are assigned a globally unique and persistent identifier
 - F2. data are described with rich metadata (defined by R1 below)
 - F3. metadata clearly and explicitly include the identifier of the data it describes
 - F4. (meta)data are registered or indexed in a searchable resource
-

To be **Accessible**:

- A1. (meta)data are retrievable by their identifier using a standardised communications protocol
 - A1.1 the protocol is open, free, and universally implementable
 - A1.2 the protocol allows for an authentication and authorisation procedure, where necessary
 - A2. metadata are accessible, even when the data are no longer available
-

To be **Interoperable**:

- I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
 - I2. (meta)data use vocabularies that follow FAIR principles
 - I3. (meta)data include qualified references to other (meta)data
-

To be **Reusable**:

- R1. meta(data) are richly described with a plurality of accurate and relevant attributes
 - R1.1. (meta)data are released with a clear and accessible data usage license
 - R1.2. (meta)data are associated with detailed provenance
 - R1.3. (meta)data meet domain-relevant community standards
-

Appendix 5 Overview of FNH-RI’s Knowledge Platform COMFOCUS

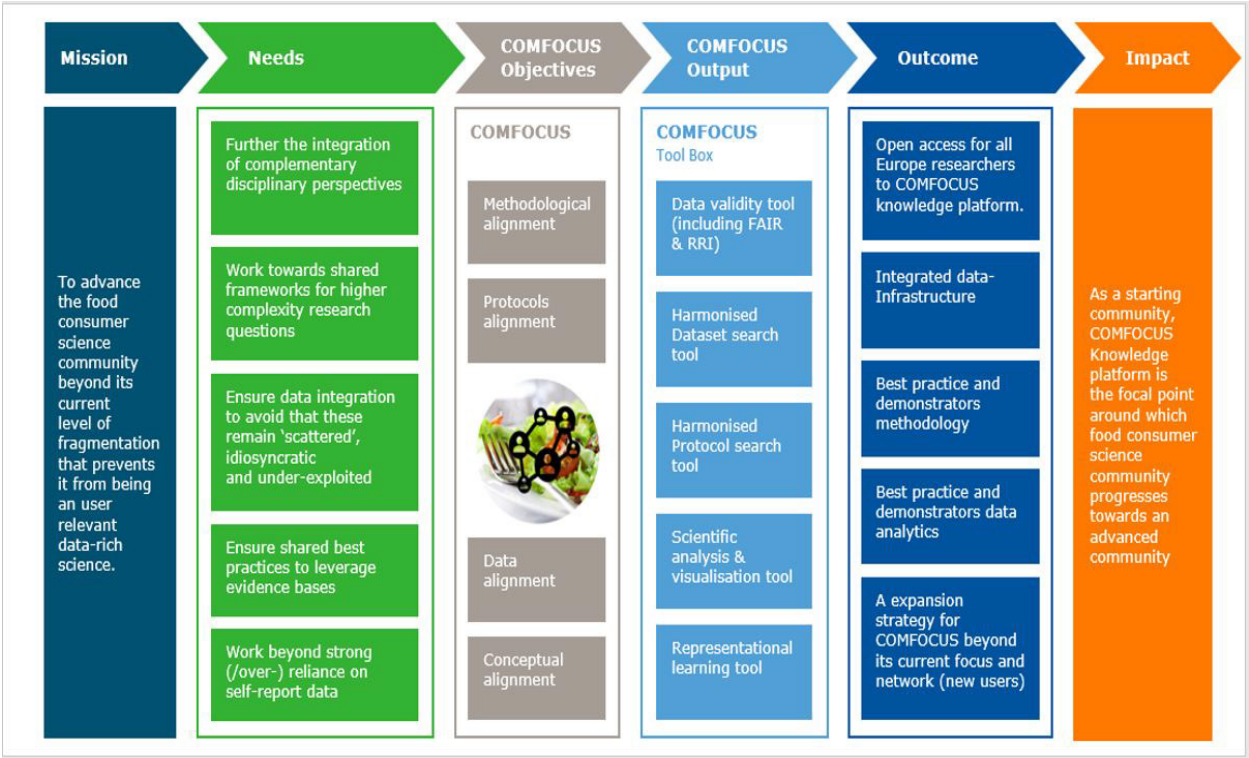


Figure Main parts of COMFOCUS

Appendix 6 The ENPADASI principles

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- | | |
|------|--|
| E1: | The provision of individual participant data should be promoted, incentivised and resourced so that it becomes the norm in clinical research. Plans for data sharing should be described prospectively, and be part of study development from the earliest stages. |
| E2: | Individual participant data sharing should be based on explicit broad consent by trial participants (or if applicable by their legal representatives) to the sharing and reuse of their data for scientific purposes. |
| E3: | Individual participant data made available for sharing should be prepared for that purpose, with de-identification of data sets to minimise the risk of reidentification. The de-identification steps that are applied should be recorded. |
| E4: | To promote interoperability and retain meaning within interpretation and analysis, shared data should, as far as possible, be structured, described and formatted using widely recognised data and metadata standards. |
| E5: | Access to individual participant data and trial documents should be as open as possible and as closed as necessary, to protect participant privacy and reduce the risk of data misuse. |
| E6: | In the context of managed access, any citizen or group that has both a reasonable scientific question and the expertise to answer that question should be able to request access to individual participant data and trial documents. |
| E7: | The processing of data access requests should be explicit, reproducible and transparent, but, as far as possible, should minimise the additional bureaucratic burden on all concerned. |
| E8: | Besides the individual participant data sets, other clinical trial data objects should be made available for sharing (e.g., protocols, clinical study reports, statistical analysis plans, blank consent forms) to allow a full understanding of any data set. |
| E9: | Data and trial documents made available for sharing should be transferred to a suitable data repository to help ensure that the data objects are properly prepared, are available in the longer term, are stored securely and are subject to rigorous governance. |
| E10: | Any data set or document made available for sharing should be associated with concise, publicly available and consistently structured discovery metadata, describing not just the data object itself but also how it can be accessed. This is to maximise its discoverability by both humans and machines. |
-

Appendix 7 The FENS poster

Collaborative Governance for Smart Food Intake

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Artem Khlebnikov (Danone), Svetlana Gutjar (FrieslandCampina) Jettie Hoonhout (Philips), Leon Frenken (Unilever)
Desiree Lucassen, Edith Feskens, Pieter van 't Veer (Wageningen University)



Current status

Making an enduring collaboration attractive

Enthusiastic work in progress on joint needs to understand food intake and food choice motives + develop costumer engagement
Co-creating methodologies and data with an integrated approach

Necessary

Link food intake and its determinants including context

Collaborate on how to achieve insights

But: lack of tradition in collaboration on data collection and sharing of pre-competitive data

Now: time is right (emerging ICT & Research Infrastructures FNH-RI)

New governance needs raising: Rules and roles of play for data storage, access, usage - the division of rights & responsibilities

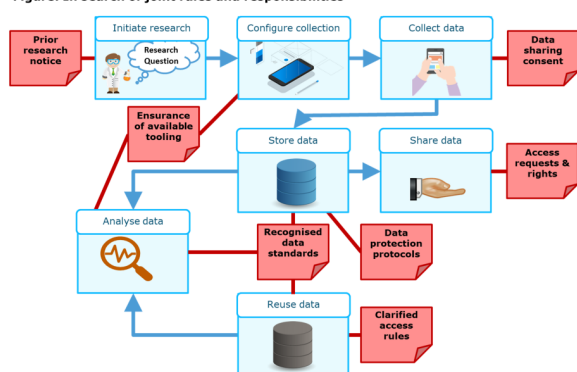
Governance objective

Establish workable rules for collaboration during and beyond the project

Methods to develop the governance

- **Triggering enduring engagement:** ongoing series of meetings (i.e. workshops, partner meetings) on precompetitive data sharing based on use cases and discussions
- **Joint trainings:** with (dummy) datasets; partner workshops
- **Real collaboration:** whole process from methodology development and data gathering, storage, sharing and usage

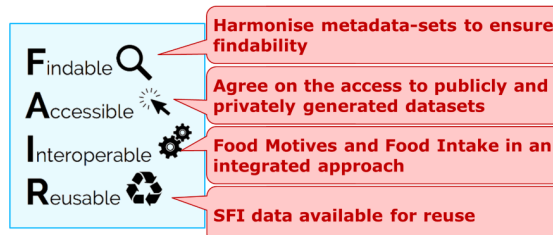
Figure: In search of joint rules and responsibilities



Preliminary rules of play

- **Prior notice** to the partners of planned research work
- **Data sharing consent needed:** consumers and consortium
- **Recognised data standards:** agreement on data descriptions and formats and metadata standards
- **Data safety first:** data protection ensures de-identification to minimise risk of reidentification
- **Access requests & rights:** explicit, reproducible and transparent, with minimal bureaucratic burdens
- **Clear ownership of data:** for every organisation and consumer; per dataset, variables, time-range

FAIRification challenges



Discussion

- Create a culture for collaboration and trust & commitment with mixed interests (collaboration is a mean, not a goal).
- Arrange explicit broad consent for sharing and reuse of data when this is not common practice.
- Decide rules for the future with a demanding regulation (GDPR).
- Dealing with WHAT IFs: rights & responsibilities with new partners & technologies; future ownership of data if organisations stop or split; future use of joint tool & data.

•Next: a post-project consortium agreement & an SFI-2

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