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Designing a world-class infrastructure to facilitate research

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Final report with recommendations for a new framework for future collaboration and interfacing between existing RIs and the RI Consumer Data Platform

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Executive Summary

RICHFIELDS aims to design a world-class Research Infrastructure facilitating the collection, connection, comparison and sharing of information and data relating to food behavior and lifestyle in EU consumers. Within Phase 2 of the project, WP9 aimed to assess the current RI landscape, and to identify, analyse and test the feasibility of implementing or linking with data and supporting information (both technical and content) from existing and new RIs and related platforms, structures and networks. A number of successful and emerging RIs exist that could be relevant to the RICHFIELDS Consumer Data Platform, including RIs with ERIC status (e.g. BBMRI, ECRIN), and other RI-like platforms, networks and project outputs (e.g. EuroFIR, GloboDIET, Quisper). WP9 consisted of four case-studies (CS), which selected relevant RIs and networks to assess covering the four 'pillars' from the EuroDISH project (Determinants, Intake, Status, Health). The case-studies reviewed the current position, gaps and needs in relation to food composition data (CS1; D&I pillars), dietary intake for population-based intake assessments (CS2; I pillar), clinical intervention studies (CS3; S&H pillars), and diet, health and lifestyle information (CS4; H pillar). Each case study embodies a specific part of the evaluation of each dataset or tool with regard to the following key questions:

- How are the datasets and data used within relevant applications structured?
- How are IC technologies used to make the data available to users and how/where is the data stored?
- How do the data producers evaluate data access, exchange and link data to external RIs?
- What are potential ethical issues related to linking into a RI?
- What recommendations can be made on the design of future data structures and interfaces of datasets and applications?

The overall objective of the Phase 2 activities was to provide information and general recommendations for designing the final Consumer Data Platform in Phase 3. All concrete decisions regarding the design of the RICHFIELDS RI will be undertaken in Phase 3, taking in to consideration the information presented from Phase 2. This deliverable builds upon the work presented in D9.1, and draws together final conclusions and recommendations from the case-studies for the design of the RICHFIELDS platform:

Data structure:
- A single RICHFIELDS ontology covering food, nutrition and health is necessary to allow harmonisation and linking of data both within the platform and with other external sources. This should be harmonized to other food, nutrition and health ontologies that are already being developed.
- Existing food classification and description systems need to be included in datasets to allow food entities to be matched and integrate datasets across different themes
- Specific training for data producers and compilers should be a component of the RICHFIELDS offering to ensure that data are captured, shared and handled in a uniform and appropriate way, utilizing any relevant data standards and SOPs that are available

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IC-technology and data storage:

- Significant investment will be needed to build technical capacity (both infrastructure and human resource) to ensure long term sustainability of the platform. The anonymisation and harmonisation of data requires considerable time and investment, both at the start of development and ongoing throughout the RI's lifespan. The platform must not be under-resourced, which must be reflected in the business plan.
- Tools to enable data sharing and effective use of data should be made available from existing RIs to the RICHFIELDS platform, and RICHFIELDS should be central to further tool development in order to maintain relevance.
- Systems for data administration and maintenance should link to management of governance and ethical issues
- Where data is held by an existing RI, links between RICHFIELDS and the other RI via a virtual link is likely to be a practical and relatively straight forward option
- The EuroFIR approach to acquisition, harmonization and access to food composition and related data is a model that has proved to be sustainable and should be considered for the RICHFIELDS platform

Governance and ethical issues:

- A comprehensive policy for platform governance and access is crucial
- A data access management board should be considered to manage the process of allowing access to and use of data
- Ethical issue challenges regarding sharing of data must be considered in the mainstream of the RICHFIELDS platform design
- The RICHFIELDS/FNH-RI platform should be a stand-alone system that is connected to other information systems and e-infrastructures via a range of web services. This should allow RICHFIELDS to maintain control over ethical and governance issues.

The recommendations include current gaps or limitations to potential RI links or data sharing that would need to be addressed to ensure successful platform development, and also highlight governance and data sharing models that have been shown to work in practice. It is essential that the design of the new RI incorporates the experience of the development of existing RIs, that relevant existing and emerging RIs are incorporated in to (or linked to) the platform (rather than duplicating efforts), and that ethical considerations inform the design and are at the heart of the data structure. The points summarised in this document are designed to provide information to the Phase 3 work-packages, to be assessed alongside other sources of information and example RIs and networks, in order to arrive at a potential design for the Consumer Data Platform