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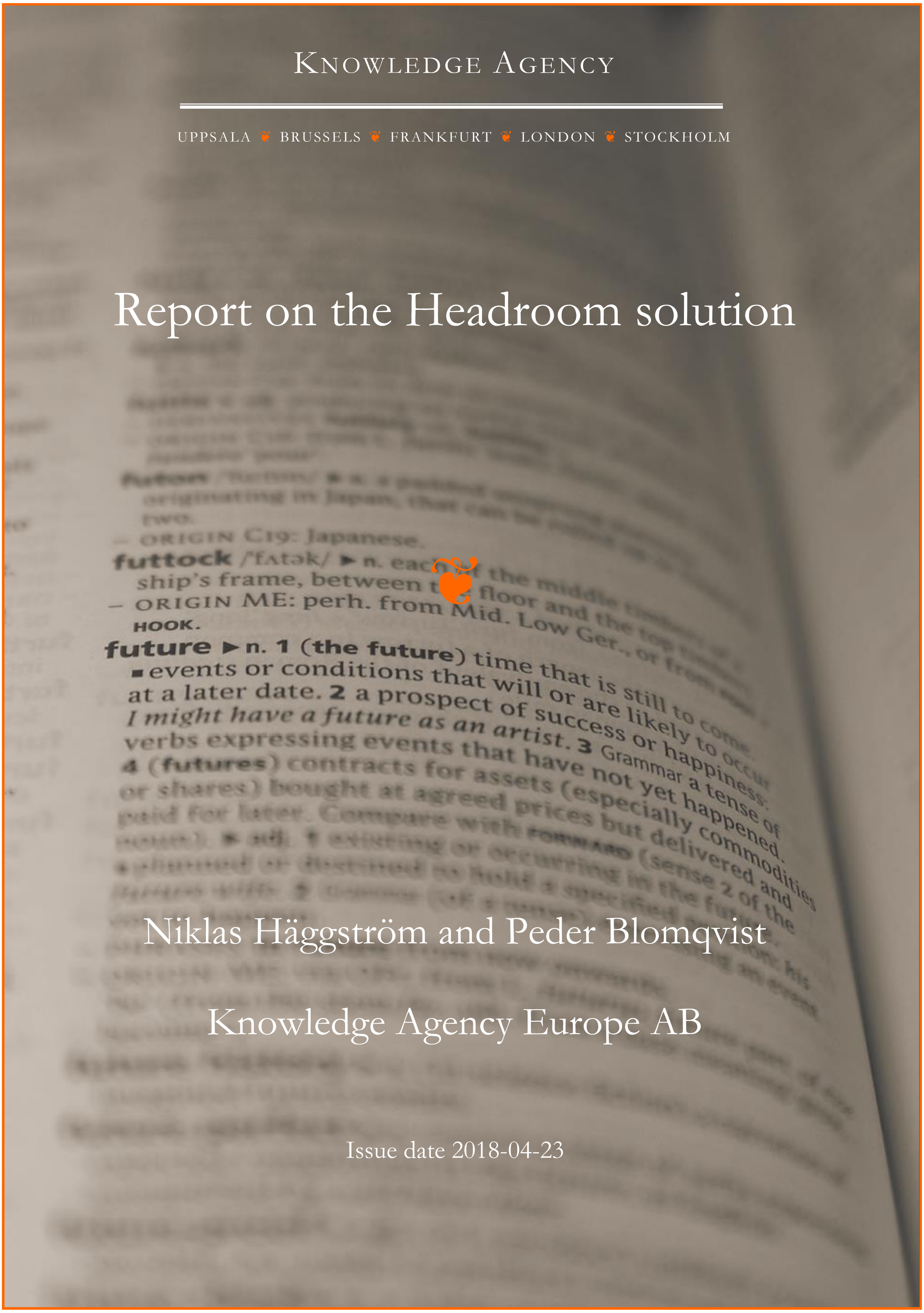

Report on the Headroom solution

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Table of Contents

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1. Executive summary

Headroom is a solution to describe, store and securely share knowledge in a digital format using a commonly understandable semantic data structure. This data structure allows both humans and computers to interpret it and absorb the knowledge it represents, irrespectively of the languages they understand.

The vision is that:

"All knowledge, and the underlying data, can be created, used and shared between humans and machines, in their capacity of citizens, companies and agencies, in a standardised, controllable and universally trusted way." [1]

Headroom includes a distributed and open source infrastructure that allows the data to be shared with those that need, and are allowed, to access it. Data is always stored together with references to its context, including what the semantic meaning of the data is, who owns it, when it was created, who created it etc. Using these contextual references, it is possible to discover data and control who has access to it. It also enables the ability to define policies for when data should be made available. A patient can, for example, share personal information with a medical doctor for a specific purpose and during a specific time.

Some services and data in Headroom are common to all users and need to be non-exclusively available to anyone who want to make use of headroom. To ensure that these services can be provided to everyone, in a democratic way, a neutral trust called Origo is intended to be put in place to control and govern the infrastructure and services. This trust will never have access to the underlying data but control who can operate in the solution and validate the code to ensure legal adherence.

Knowledge Agency Europe AB has by this report performed an independent study of the Headroom solution which concludes that that the Headroom solution in many aspects has a high degree of innovation which has great potential to improve the way information is managed in the future.

Headroom can become very beneficial for many organisations and individuals giving them the ability to securely share knowledge and information across existing domains, national and legal borders, while still maintaining control of data usage and dissemination. However, while the conceptual idea and achievements so far show good potential, there is a need to make further progress in several areas before the true benefits can be reaped.

The Knowledge definition services which allows to describe and share concept descriptions in any language is the most mature part of the solution and can relatively quickly become a valuable tool foremost in ongoing standardisation activities related to semantic interoperability.

Once definitions of knowledge are created in the solution, it will be possible to integrate existing systems to increase the value of their data and allow data owners to share sensitive information in a trustful way. This part of the solution, however, requires further development and validation in real life examples.

The full value of the solution will appear when a significant amount of data is in the solution and when services operate directly on the Headroom infrastructure as it will enable a rich framework for processing data without ever exposing it to the users. Activities need to be performed in this area to prove that the solution will scale and to establish confidence for current actors to move their data.

Lastly, the governance regime of the solution and the Origo organisation raises several open questions related to financing and ownership which must be resolved before the whole solution can be put in place.

[1] Headlong Development AB, 2018

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2. **Engagement overview**

2.1. Background and objectives

The Headroom solution is developed by Headlong Development AB within the Swedish NIMI Initiative, with an initial application in the field of medical informatics. The goal is to create a logically common, storage service that can manage all patient-oriented data in the Swedish health care system. This system shall reside outside of the institutions and IT-Systems of today, enabling patient data to be used in transversal processes covering multiple actors in the health care system while being controlled by the true owner of the data – the patient.

This document is an independent study and analysis of the Headroom solution performed by Niklas Häggström and Peder Blomqvist at Knowledge Agency Europe AB as part of a project funded by Vinnova (Sweden's innovation agency). The purpose of the study is to describe and analyse the technical and informatics foundation of the Headroom solution to clarify and deepen the documentation of the solution. This has been done in the form of an architecture-based conceptual analysis.

Knowledge Agency (KA) consists of an international network of renowned independent specialists within the field of information management and digital innovation, all with many years of national and international experience. The network includes over 200 consultants of different competence backgrounds such as information technology professionals, information strategists, professors, researchers, and operations experts. Knowledge Agency has no relationships or dependencies to the other organisations participating in the NIMI initiative.

Another part of the overall project run by Headlong Development AB will demonstrate how the information contained in Fass (National Pharmaceutical database in Sweden) can be stored as per the new principle and made available in a format tailored to the needs of patients and health care personnel. This implies defining the information that is available today, supplement it with information that is today missing and, with the help of the modelling done in part of the project, describe the solution.

2.2. Approach

The description of the Headroom solution is based on material received from Headlong Development AB and has been complemented by interviews with Robin Jeffner and Jens Eliasson from Headlong.

The received material, see chapter 0, is of varying quality and depth which has resulted in a need to perform several interviews. The most noteworthy difference between material and interviews is that the written material almost completely lacks references to studies and research while the interviews shows the opposite – the Headroom solution is developed on a sound research background, mainly in the area of ontology.

The authors have used their long experience in Information Management and Enterprise Architecture to analyse the received input and explain it in a structured way aligning with best practices and common knowledge in the area.

All chapters in the report except those marked with "KA conclusions and recommendations" are reviewed and agreed with Headlong Development AB. Chapters titled "KA conclusions and recommendations" have not been shared in advance with Headlong.

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3. **Wicked issues and challenges**

Big investments are made by governments to provide equal and effective services to the citizen's, but some problems seem always to remain unsolved, no matter the size of budget, number of actors involved or legal and political pressure.

We call these problems "wicked issues" and will later in the report explain how the Headroom solution promises to address them.

In summary:

The Headroom solution address a series of issues related to definition and exchange of data, including:

- *How to enable a well-functioning digital ecosystem for individuals/citizens and public and private organisations*
- *How to describe knowledge in a universally understandable way, for both humans and machines*
- *How to encourage and establish trust in sharing information and knowledge between stakeholders in an ecosystem*
- *How to establish a persistent link between knowledge definitions and data across data islands*

3.1. Non-functioning digital ecosystem

Ecosystems of today are affected radically by the current digitization. Today, there are very few initiatives at European or national level to manage or support existing digital ecosystems (micro or macro level) to remain viable for the future.

To manage and support digital ecosystems, fundamental conditions and understandings are required. The shift from a product- to a service-oriented logic and approach, socio-technical processes of digitalization and digital innovation challenge assumptions between tangible and intangible innovations. In a digital ecosystem individual, public and private organisations become increasingly dependent on each other and there is a need for a flexible infrastructure that supports not only information exchanges of information, but also exchange of knowledge and the collaborative creation of it cross-organisations.

The fundamental characteristics of an innovative digital ecosystem which challenges the traditional product-oriented approach are:

- Digital material at its core is immaterial,
- Digitalized technologies allow flexible and multiple content use by separating physical hardware and the digital information and knowledge that comes with services
- Process of digitizing has the potential to remove previously tight couplings between specific information, knowledge and the associated transmission technologies. Storage formats, and processing technologies.
- Digital innovation becomes a self-referential property of digital technology, meaning that one needs digital technology for digital innovation.

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3.2. Ineffective and separated definitions of concepts

Data needs to be understandable. If the meaning of data cannot be understood within a certain domain of knowledge, it will result in miscommunication and inability to take correct decisions on the data.

A major challenge to the understanding of data is that the human understanding of something is conceptual while data is specific, or instantiated, like text. An example is the conceptual idea of a Car which is universal, but to describe it using text, which can be stored as data, we use many different words in different languages and slang. To handle the complexity in data comprehension, the healthcare, and other sectors, have made significant investments and efforts over the years to form harmonized and common informatic structures and standards. Yet, the benefit from these initiatives are limited due to the vast complexity in the number of actors that need to participate and the many applications of the definitions.

Concept

*noun con·cept \ ˈkän-ˌsept *

1: something conceived in the mind: thought, notion

2: an abstract or generic idea generalized from particular instances

- Merriam-Webster online dictionary

Current standardisation initiatives are slow and resource-intense. The standards need to be limited in scope to be manageable and they are outdated the moment they are published. Furthermore, many of them do not relate to previous versions and other standards.

In addition, most standards define dictionaries (terms) for concepts, but rarely how the concepts relate to other concepts. While this is useful for converging towards a common language, it adds limited progress towards a common knowledge of the topic at hand.

Furthermore, the definitions are in most cases separated from the data that uses them. This means that it is not possible to discover data based on the standardised concepts or explore related concepts based on existing data. At best, there are separate search engines that builds indexes between the concepts and the data, but this requires full access to the data which is not always feasible.

3.3. Islands of data

It seems impossible to provide the ability for both patients and health care providers to follow an individual throughout the whole health care process, regardless of where the information has been registered or documented. The same applies to other sectors.

Agencies, municipalities and providers of societal services fail to make data available to the owners and other potential users, in most cases due to conflicting laws and regulations, but also lack of government directives.

Private actors, for many good reasons, cling on to data like gold which results in data islands with an inefficient ability to collaborate and lost business opportunities. There are few legal and financial incentives to advertise and share data in a digital format.

The data in these islands lack attributes to enable it to be visible and discoverable outside traditional boundaries. If the data is not discoverable in a shared space, available to be used as an asset, it will not add any value outside the remits of the data owner.

Furthermore, as there are no governance mechanisms available for shared data, the integrity and validity of the data is not known to its users and data is dispersed in multiple locations without any trace to the original source.

Obstacles like governance, standardisation of technologies, education, agency requirements, government directives and political issues are all causes of this problem.

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3.4. No control of data usage

No single organisation or person has full insight to as where their data is used and no technical means to monitor and control the data usage. The only instruments at hand are laws, regulations and agreements which most people are unaware of or do not understand. As these agreements are separated from the actual data, there are no possibilities to ensure that they are enforced.

At the same time, organisations want to ensure that appropriate safeguards and measures are in place to protect sensitive information and minimize risk. Despite the recognition of the importance of the issue, many organizations do not have formal information governance programs, or coordinated information management strategies in place.

The effect is a generally increased resistance to advertise and share data which would not be the case if the data owner could easily track and control of where their data is used.

3.5. Constraining and demanding laws and regulations

Management and usage of information assets are regulated by national and/or international laws, rules, regulations and corporate policies. If protected information (internal or external) is shared to the wrong actors or used in a wrong way, there is a risk for the consumers in terms of operational or business impacts, and for the provider of the information it will be a matter of legal implications and most likely a risk of lawsuits.

The GDPR (General Data Protection Regulation) will impact all information relating to an identified or identifiable natural person ('data subject'); such as a name, an identification number, location data, an online identifier, or factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that person.

Organisations also have a need to ensure protection of distinctive signs, trademarks, names, geographical indications, innovation, design and the creation of technology, like patents, designs, trade secrets, ideas, concepts, plans and descriptions, contracts and agreements.

Not many organisations have the full capabilities to ensure completeness, accuracy, correctness and authenticity of its digital information assets. The implications of this inability is that individuals and organizations are experiencing increased difficulties in ensuring and demonstrating adherence to laws and regulations.

In addition, laws and citizen expectations are pushing for a higher rate of change, greater transparency, better security, increased situational awareness and accountability.

3.6. Trust based on individual's preferences

Trust is about knowing things well enough to feel comfortable to take decisions and actions in real life. The concept "trust" often relates to human perspectives and must be treated as such to build trusted relations. The level of trust in the context of "information" and "information sharing" is about ensuring transparency in how information is used and ensuring that it is not shared without consent.

The background is that there is a human predilection to guard what is "ours". The information we hold and the resources we use to create it are no exception. Furthermore, we have a classic industrial-age mindset toward the implementation and management of information systems and the information that they create. Individual agencies and organizations does not seem to be motivated enough to treat information between multiple actors and individuals as a shared asset.

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Information, today, is an important competitive factor. Therefore, the ability to retrieve reliable and usable information is vital. It must also be possible to protect the information and distribute it only to those authorised to access it.

Another limiting factor are the organizational cultures that do not provide incentives to share information – a “willingness to share”. This is understandable, but not very efficient from a societal or operational perspective. We must overcome these limitations and see the goal of the collective as more important than the individual organizations view.

As of today, there is no neutral, secure and transparent platform for information sharing available to ensure that individuals and organisations trust to share their sensitive data for the good of the collective.

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4. The strategic perspective of Headroom

This chapter describes the vision and the strategic perspective of Headroom. This includes the capabilities that Headroom provides as well as the principles it is based upon.

The Headroom solution provides the ability to define knowledge in a universal language that can be understood by humans and machines. It also enforces stored data to be linked to the knowledge definitions which enables tracing and consistency in collaboration between organisations. Furthermore, the Headroom infrastructure allows data to be stored once only and shared many times in a trustful way.

4.1. Headroom vision

"All knowledge, and the underlying data, can be created, used and shared between humans and machines, in their capacity of citizens, companies and agencies, in a standardised, controllable and universally trusted way." [2]

A vision where each data owner has a complete control and situation awareness of its data, and the use of it in different contexts and processes. For example, to follow it throughout the whole health care process, retrieve all information from various actors and decide who has access to what.

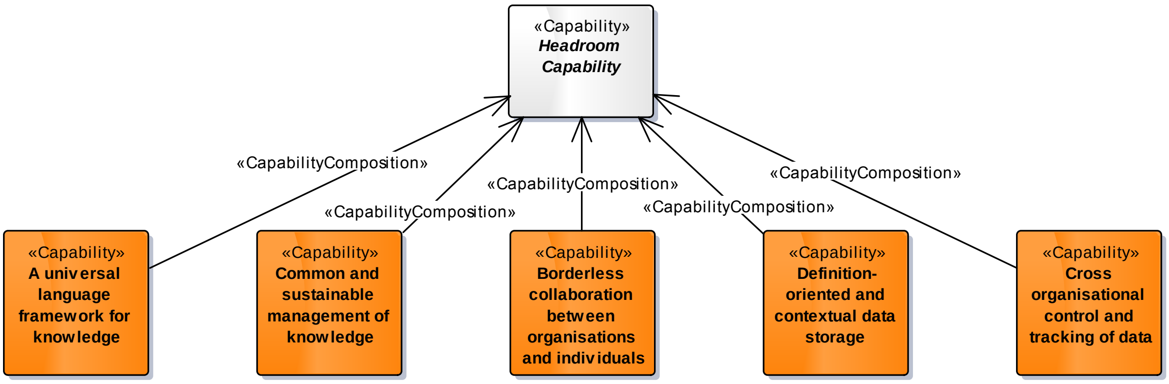
4.2. Headroom capabilities

The headroom vision would certainly be one major step forward towards a common knowledge base and standardised semantic tool for a society and for a community like the health-care sector.

If it also would be possible to use Headroom regardless of conflicting laws, regulations and where the information has been registered, documented or stored, it would increase the benefits and values significant for all actors involved in a society.

Obstacles like governance, technologies, education, agency requirements and government directives have also been overcome as well as speed limiters like costs and political issues for implementing such a common and standardised solution on a national, European or global level.

The Headroom solution provides five main capabilities:



[2] Headlong Development AB, 2018

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4.2.1. A universal language framework for knowledge

Headroom provides a common way to describe knowledge so that it can be interpreted by both humans and machines. Thereby, anyone can understand and learn from others irrespectively of their language proficiency or previous knowledge within a domain of interest.

The language in Headroom is based on three main constructs that form the basis of all concept and knowledge descriptions – Phenomena, Rules and Events. Using these three constructs, any type of knowledge can be described and interpreted.

Language barriers will be broken and inconsistencies between different taxonomies and standardised phraseologies can be overcome, leading to a more coherent knowledge base while still respecting the heterogeneity of our society and difference in opinions and viewpoints.

This will radically improve the ability to achieve interoperability and a high degree of trust, at political, legal, organisational, information and technical levels, as anyone will, in principle, be able to talk to anyone else using their own words. It will improve the ability for different actors of collaborative knowledge creation, evolution and sharing across borders and organisations.

All the knowledge follows a structured format that can be interpreted by machines, the ability to automate processing and creation of new knowledge is greatly enhanced. Machines can be programmed to read, analyse and draw conclusions in a very efficient way with high accuracy.

To summarise: this capability mitigates the following wicked issues:

- Non-functional digital ecosystem
- Ineffective and separated definitions of concepts
- Trust based on individual's preferences

4.2.2. Common and sustainable management of knowledge

Headroom gives the ability to describe multiple definitions and versions of concepts and the linkages between these. This allows for an evolution of languages and dialects while still maintaining traceability to its heritage.

Furthermore, any piece of data is always stored in the context of its defining concept. This means that nothing can be stored without its semantic meaning, resulting in that all information in the Headroom solution represents knowledge.

The versioning of concepts and contextual data storage enables a unique ability to traverse between knowledge of different sources. As an example, the understanding of a phenomenon as per the ancient Greeks can be easily translated to modern day English or vice versa.

As Headroom separates the definition of concepts from the data that uses them, it is also possible to display the same data in multiple languages or information standards at the same time. This might for example be helpful when proving compliance to data protection requirements in multiple countries or presenting the content of a medical drug to both patients, in a simple language, and medical doctors, in full.

To summarise this capability mitigates the following wicked issues:

- Non-functional digital ecosystem
- Ineffective and separated definitions of concepts
- Constraining and demanding laws and regulations

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4.2.3. Borderless collaboration between organisations and individuals

Using Headroom, an organisation or individual can share data and knowledge with anyone without sending copies of it to the other party, thus avoiding islands of data being created.

Unlike traditional integration platforms which distributes data between the stakeholders, the Headroom infrastructure manages data and gives authorised parties access to the same piece of data, irrespectively of where they are located.

Data is stored once and reused in many places which ensures data consistency, and therefore trust, between the stakeholders. In addition, all data has an owner who can control who has access to it and under which circumstances. The effect is that a data owner can, for example, decide to share a medical record with a medical doctor to assist in the establishment of a certain diagnosis. Once the diagnosis has been made, the data access rights can be restored to the original state.

Data sharing can also be done at a very granular level. In comparison, instead of sharing a complete document with someone, the data owner can decide to share only a part of the document, without having to cut the document into parts and send these parts. This is of particular interest when discussing sensitive pieces of information such as personal details which is regulated by law.

As mentioned above, the ability to link data to concepts, in different languages, is also of great value when collaborating across organisational and national boundaries.

To summarise: this capability mitigates the following wicked issues:

- Non-functional digital ecosystem
- Islands of data
- Constraining and demanding laws and regulations
- Trust based on individual’s preferences

4.2.4. Definition-oriented and contextual data storage

Headroom gives an inherent ability to view all data in its context, including to which concepts it is related, who the owner is, which function has created it etc. This contextual data storage leverages the value of the data as the context for example can be used to identify what the semantic meaning of the data is, in multiple languages, and how it was created.

The ability is achieved by separating the storage of definitions from the storages of data while still maintaining links between the two dimensions. The separation allows for the definitions to be available to a broader group than the actual data, allowing consumers to discover data based on the concepts that they are interested in. I.e. a consumer can search for data using the definition database and then request access to it once found.

To summarise: this capability mitigates the following wicked issues:

- Ineffective and separated definitions of concepts
- Trust based on individual’s preferences

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4.2.5. Cross organisational control and tracking of data

Headroom allows for all data creations and usages to be controlled and logged for later review. This gives data owners control of its data regardless of where it has been produced, stored or used in the Headroom infrastructure.

Each data owner will have their own logical database for personal or organisational data storage to which they control the access. At the same time, there are some of this personal data that are required by law to be shared with government agencies. The Headroom infrastructure ensures that policies are put in place to fulfil these legal requirements while maintaining the individual or organisation as data owner.

All data usages are logged and allows the data owner to track and provide evidence of to whom data has been presented.

To summarise: this capability mitigates the following wicked issues:

- No control of data usage
- Constraining and demanding laws and regulations
- Trust based on individual's preferences

4.3. Headroom design principles

The headroom solution design is based on a set of main principles, as follows

4.3.1. Digital ecosystem for developing information services

Headroom is designed to enable a multitude of different actors to create and makes use of services for sharing information and knowledge. A digital ecosystem includes platforms that serves as a core on which multiple actors can contribute to extend the service possibilities of the platforms. Services like information-, and knowledge sharing are fundamental for viable digital ecosystems. It also includes various actors like platform owners and various contributing people and organisations as well as regulatory regimes focusing on interoperability standards that bind these heterogeneous actors together.

The tension between those different actors and the need of a flexible infrastructure for sharing knowledge lies at the heart of digital ecosystem innovation. Experiences so far shows that the issues of managing digital ecosystems innovation is very much related to find the right balance between actors seeking to engage in generative acts further expanding the platform ecosystem, and the opposing actors serving the role as regulators accepting or rejecting this generative attempt.

Origo is a work name of the open and transparent organization or role that is supposed to be the one who owns the Headroom platform when the system is sufficiently complete for general use of the entire functionality. It is Headlong Development AB, which develops and owns all rights to Headroom today.

Headroom means "room for thought" and is the name of a method and model for general management of knowledge and data in a globally distributed computer system. When a fully functional implementation of the model has been built a takeover negotiation with Origo is proposed to take place. Headroom design and the approach taken will therefore most likely ease the tension in a digital ecosystem.

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4.3.2. Cross-Organisational value by design

Value by design constitutes user value and how design can contribute to its creation

In the Headroom context, value by design means that the approach taken is to facilitate and promote cross-organisational value by offering new way´s for users and developers to interact and reuse knowledge cross organisational and knowledge domains.

This will help to improve the way of working in many organisations and business, e.g. in health care this can open new ways of how to design- production, safety and reliability, measurements of outcomes and performance of a future health-care cross-organisational organisation or digital ecosystem communities.

4.3.3. Privacy by design

Privacy by design is an approach that promotes privacy and data protection compliance from the beginning in a system or a concept development project. Often, these issues are bolted on as an after-thought or ignored altogether but will certainly help organisations comply with their obligations under the legislation if implemented.

In other words, privacy by design is not about data protection but designing information systems so data doesn't need protection. In headroom this approach has been taken care of as default in the concept. The importance of this design principle shows already in the Headroom vision statement "All knowledge, and the underlying data, can be created, used and shared between humans and machines, in their capacity of citizens, companies and agencies, in a standardised, controllable and universally trusted way."

4.3.4. Ontology approach

All concepts and knowledge descriptions in Headroom follows a formal specification – an ontology approach.

The word ontology originates from philosophy, where it means a systematic explanation of being. Within the knowledge engineering community, ontologies are defined as "an explicit, formal specification of a shared conceptualization".

The Headroom ontology defines a set of concepts that can be used to describe knowledge in a consistent and universal way. The ontology in headroom is defined at a meta level which means that it defines a set of concept types that can be further used to describe real-life concepts. This allows to overcome and mitigate the difficulties raised by monolithic, isolated knowledge systems and to specify content specific agreements to guarantee consistency and facilitate knowledge sharing and reuse among systems that submit to the same ontology/ontologies.

By using the ontology approach, the Headroom solution is capturing not only the data but also the knowledge within any domain of interest. For developers of hosted services, this means that the concept can facilitate and support specific software applications and services to be developed within a specific field by using the Headroom knowledge base as an input e.g. in neural networks, genetic algorithms or other artificial intelligence specific methodologies for processing the knowledge. This capability will open new perspectives concerning the scope, the role and the power of the computational machines. In other words, if the Headroom solution proves to be successful, it will change our thinking about computers and data, and it will open better ways for human to computer interaction and human to human via computers communication.

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4.3.5. Separation and linkage of data definitions from data instantiations

In Headroom, all data instances are stored with a reference to their definition. The effect of this is that it is always possible to understand what the semantic meaning of the data is. A simple example is a data instance called Tank. This means several things in English and has meanings in other languages. But as Headroom forces all data to be stored with a reference to its definition, it is always possible to understand what the conceptual meaning is.

Data instances and definitions are also separated. The rationale behind this is that definitions should be reused and shared between many actors which data instances need to be protected.

4.3.6. All data have contextual references

Every data instance in Headroom contain attributes that explain its context. This includes which function has created it, who has initiated the function, who the data owner is etc. These context attributes are very useful when processing data and verifying its consistency. In fact, they are essential in situations which require traceability of transactions and data exchange.

The attributes are not directly visible as a part of the data instances, instead they consist of references to other data instances. This makes it possible to control who has access to which context attribute. As an example, it may not be allowed to show who is the owner of certain data elements.

4.3.7. Open source – where applicable

Relevant components of the Headroom infrastructure are intended to be published as Open Source. The rationale is twofold; to ensure full transparency in the infrastructure and to allow for extension and improvement by many actors.

As the aim of Headroom is to create an open digital platform for many actors, it is important that the actors trust the infrastructure that hosts and processes the data they own. By publishing the software code as Open Source, it will be possible for anyone to review and analyse it. It may even be accredited.

In addition, the Headroom developers realise that it will not be possible to create the Headroom solution as a one-off activity. The development need to be continuous and many actors should be given the opportunity to contribute. An efficient development regime can be achieved by having a modular design and allow different organisations and persons to contribute to the platform.

4.4. KA conclusions and recommendations

Knowledge workers of today have an increasing need to reuse and analyse data to support creation of information and knowledge, and the subsequent reuse and sharing. The challenges of achieving sematic interoperability are impossible to overcome using traditional approaches, even for the most knowledgeable in their specialist area.

If the Headroom solution can be realised in its totality, it will provide capabilities to solve some of the most difficult challenges in the information age and has the potential to change the way we describe and share knowledge and information.

The design principles demonstrate a good level of maturity in the thinking of the solution and will contribute to a well-designed solution, if followed. The principles of ontology approach, separation and linkage of data definitions and contextual data have all been proven in theory through this report and in practice by initial prototypes. The adherence to other principles are harder to demonstrate given the limited number of practical applications available.

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Thus, the main concern is that some of the capabilities described have not been demonstrated in practice. The team behind the Headroom solution has clearly developed the conceptual thinking to a quite mature level and verified the technical feasibility in creating the platform. However, there is a lack of practical demonstration of the Headroom capabilities applied in a fully-fledged digital ecosystem.

The five Headroom capabilities together creates a unique combination. At the same time, this implies challenges in terms of concept complexity for the solution developers, not least in terms of skills and the level of maturity of the experts needed for the development of the abstract levels that this concept stipulates.

Knowledge Agency recommends proceeding with the following activities related to the strategic perspective:

- *Define and describe the Headroom digital ecosystem, and from a national point of view identify actor's roles and responsibilities to find a good balance between different actors early in the process. Document and describe examples and guidance material for communication and dialogues with different stakeholders and interested communities.*
- *Ensure that operational and technical experts as well as managers from all types of actors are represented in coming development activities, including public and private organisations as well as individuals.*
- *Practically demonstrate how all actors in the ecosystem can use Headroom to achieve the identified capabilities and work together in new ways. Create conditions as early as possible in the development work to invite different service providers to test and participate actively in the design of support for hosted services in the headroom.*

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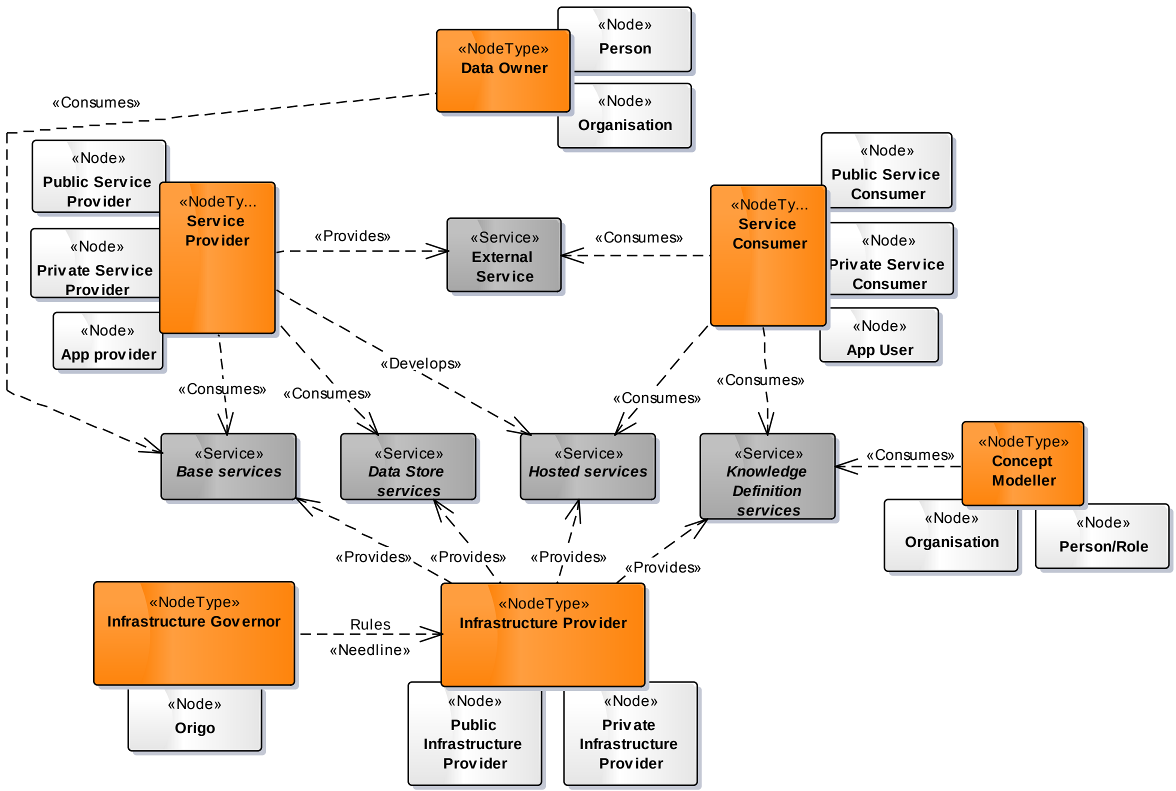
5. The operational perspective of Headroom

This chapter provides an overview of the actors involved in the realisation of the Headroom solution and how they collaborate. While this description contains some clarifying examples, it is very generic and can be applied to many different types of operations and domains in both public and private sectors.

While one or more organisations act as providers of the Headroom infrastructure, the data is protected due to EU regulations and controlled by the data owners. There is also a governing body that approves changes to the infrastructure to ensure its independence from proprietary solutions or political realms. Service providers can make use of the infrastructure to host services, thus enabling access to Headroom features and data in accordance with the data owners' policies.

5.1. The operational actors

The picture below contains Node types and Nodes which represent the different actors. Note that one organisation or person may act as multiple Nodes at the same time, i.e. have different roles. The Nodes uses Services to interact with each other.



The **Concept Modeller**, which can be an organisation, such as a standardisation body, or a person, uses the Knowledge Definition Service to create a description of their knowledge within a certain domain. This includes a description of concepts, such as phenomena, rules and events as described in chapter 6. This may for example be a description of symptoms, medical diagnosis process, possible treatments and drugs.

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Some concepts can relate to data instances, e.g. an actual diagnose for a person at a specific time and the drugs prescribed. Data instances are stored in the Headroom infrastructure and are created and read by **Service Providers and Consumers**. There are several types of data stores that hosts different types of information, e.g. personal datastore, government datastore etc. These are further described in chapter 0.

Data is provided to, and read from, the data stores by the Service Providers using the Data Store Services. With the data from the Headroom infrastructure, possibly combined with their own internal data, both private and public service providers can provide so called External Services to their clients and users.

A Service Provider can also develop services that are hosted by the **Infrastructure Provider**, which can be a private or public organisation. This means that the services may get access to data that they would normally not be allowed to if the data is kept within the Headroom infrastructure. These services go through a validation by the Infrastructure Governor to ensure that they respect the policies set up. An example of such service might be a Medical record service where the developer creates the code to get and display medical records but is never allowed to see the content of the medical records.

The **Infrastructure Governor** is an organisation that provides the rules for the Headroom infrastructure and ensures that they are adhered to. As such, it owns the property rights to the Headroom infrastructure, approves any changes to it and certifies Infrastructure Providers. The Infrastructure Governor is intended to be an organisation in the form of a trust which operates under a set of directions that guarantees its independence from any political or commercial interests. The working name for this trust is Origo, but it has not been put in place yet as the solution is not close enough to a full-blown deployment.

Each piece of data in the Headroom infrastructure has a **Data Owner**, i.e. the person or organisation which have the right to decide how it should be used and shared. This may be the creator of the data or the legal owner of it, as in the case of medical record information where an individual is the owner even though it is created by a doctor. Using the Base services of the Headroom infrastructure, the Data Owner can control and set policies for who has access to the data and under which circumstances. As an example, a patient can allow a doctor to view their full medical history but allow research scientists to only view de-personalised information about their conditions for research purposes.

Some data access policies will be regulated by law while other will be defined by agreements or on-demand requests. Important to remember though is that the Headroom infrastructure will log all data creations and reads which enables full traceability within the infrastructure and the services it provides.

5.2. Example based on Fass

An example use case has been developed in another part of the overall project, see reference 7. This use case is based on the interactions between a patient and a medical doctor who uses the Headroom solution to share information from medical records, a drug information database (Fass), some types of master data, the patients' genome and pharmacological knowledge.

The patient in this case acts as a data owner, being able to control which data is shared with the medical doctor. The patient is also a service consumer in the sense that he uses an app to view information about which medical substances he uses and are prescribed to him.

The medical doctor is also a service consumer through his medical record system which allows him to look at medical records and prescribe medications.

The use case clearly demonstrates the benefit of being able to share certain data and to analyse drugs and their effects in the context of a specific individual.

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The use case is at this stage a theoretical description and no running demonstrator has been shown. In addition, it does not consider the roles of concept modeller and service provider, i.e. how the definitions are created and how the existing systems/services, including Fass, are integrated into the Headroom solution. The infrastructure provider and governor are not included either, but this was never intended to be covered.

5.3. KA conclusions and recommendations

The main winners of the Headroom solution are the Service Consumers as the services they use will operate on far more consistent and complete datasets. Specifically, the services that are hosted in the Headroom infrastructure will add new capabilities to use rich data in an anonymous way. This opens possibilities for Service Providers to develop new services and business models where they operate on data which they do not own. The competitive advantage will appear for those that are good at analysing and using data rather than those that collect and lock it in.

The Concept Modellers also play an important role in the establishment of the solution. Without them, there will be no knowledge definitions that can be used. The way to describe concepts is very different from the way it is done in traditional standardisation initiatives. Hence, it is very likely that resistance and scepticism will be experienced until the value of concept modelling is proven in practice using real examples.

The ideas around the Infrastructure Governor and Infrastructure Provider are definitively going in the right direction, i.e. to create a governance regime that primarily serves the data owners and acts as an independent and trustworthy governor. The move from ideas to realisation of these actors is of great importance for the solution to be successful, but it will not be possible to do in the short term.

Naturally, there are many challenges surrounding this type of concept as it is very different from existing organisational and governance models. The main one will be how to get organisations and individuals to move their data into the platform. This will not happen until a significant level of trust is established for the platform and its governance.

Knowledge Agency recommends proceeding with the following activities related to operational and governance issues:

- *Further detail the roles of the Infrastructure Governor and Infrastructure Provider, including principles for governance and the terms for the Origo trust.*
- *Realise the Knowledge definition services and convert a limited set of existing standards to the new format to demonstrate backwards compatibility. Then offer the service to existing standardisation bodies to drive global adoption.*
- *Continue to work on real-life application examples such as Fass, focusing on realising and demonstrating smaller parts of the solution. Seek examples outside the health domain to ensure that the solution does not become specific to one industry.*
- *Finalise the Fass example, focusing on Data Owners data sharing consent and how a hosted service can make use of confidential data without exposing it to the Service Consumer.*

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6. The information perspective of Headroom

This chapter describes how the information content is structured in Headroom to make it comprehendible for those that shall use and store it, both human and machines.

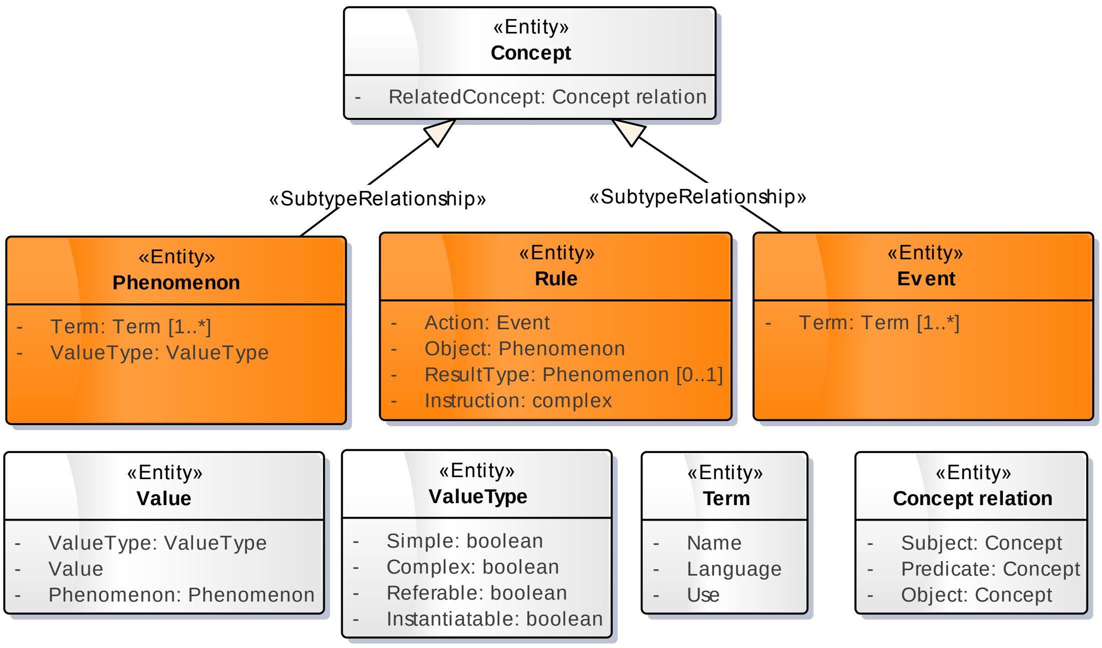
The information structures in Headroom are designed to be a universal framework for description of knowledge that can be used in all languages and notations. In its essence, it consists of three constructs: phenomenon, event and rule. These constructs provide a structured way of describing concepts that can be understood by the human mind and utilised for machine enabled cognitive augmentation.

The Headroom solution aims at bridging the analogue and digital realms, but it also aims at creating a knowledge base of definitions that can evolve naturally over time. It also ensures that it previous knowledge is maintained so that all data can be viewed in the context of where it was created. This is important as languages and understanding of concepts will evolve over time, but we need the ability to look at past versions of the knowledge.

6.1. The foundational description elements (Meta-ontology)

At the heart of the universal framework is a set of three types of elements that are used to describe any concept that can be understood and acted upon by humans and machines – Phenomenon, Event and Rule.

The main elements and their attributes are depicted below.



A **Phenomenon** is a fact or thing that is observed to exist. As this is a very broad definition, phenomena are categorised in ontological taxonomies, i.e. they are generalised and specialised using Concept relationships. Concept relationships are defined by a subject, object and a predicate. Examples of phenomena and relations between them are: Volvo XC90 is a Car, Medical Doctor is an Occupation, Kilogram is a Measure of Weight, Asthma is a Lung Decease etc.

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Most Phenomena can be instantiated as Values. This is one of the main features of the Headroom solution as it creates a link between the definition of data and the actual data instances and the system keeps track of this link. The effects are that any data instance can be traced to its semantic concept, in any language where it has been defined. It also means that it is possible to search for all data instances of a certain phenomenon that the user has access to.

Events are activities or things that happen or are done. Examples are Build, Educate, Measure, Diagnose, Treat etc. Events can also be related to computing activities such as read, create, store etc. This means that they can be used to create computing rules in the Headroom solution.

Rules are process instructions that can be used for automated or human execution. They are formed by linking phenomena and events and as such they form terms at a language independent, conceptual level. An example is Diagnose Asthma which is a link between the event Diagnose and the phenomenon Asthma. While the phenomenon and event can be described in multiple languages (terms), the rule is still applicable. Rules can also have results, which in this case would be a Diagnosis. They may also have instructions that gives one or more directions on how to create a result. Instructions define how the event need to be performed in the context of the phenomenon. For example, how a medical diagnosis need to be performed for an illness.

While not shown in the information model, the phenomena, rules and events are also linked to user roles in the Headroom solution which allows to define who has the authority to see data or perform actions (execute rules) in the system.

6.2. Definitions, Instances and Reference instances

The information in Headroom is divided into two main layers; the definition layer and the instance layer.

In the definition layer we can find all concept **definitions** in the form of phenomena, rules and event descriptions. The definition layer is in general accessible by anyone without limitations to ensure that definitions are reused in as many contexts as possible.

In the **instance** layer, the actual values are located. This information is in general only available to authorised users and services as it contains information that is owned by specific individuals or organisations. However, some instances are of public nature and need to be unique in the whole system. Such instances are called **reference instances** and examples are the elements in the periodic table, which should be uniquely defined once and then reused many times.

The information in the definition layer and the instance layer are linked to each other by unique references. This gives the ability to identify information instances based on open definitions at a system-wide scale. Naturally this depends on the existence of instances in the system and authority to access it, but as the instances are described at a granular level it will for example be possible to perform queries of all asthma diagnoses, applied treatments and effects across Europe without ever exposing the identity of the persons that were diagnosed.

The link between layers also ensures that any instance always can be traced back to the definition that was used when it was created. The Headroom solution also includes a versioning system which ensures that the definitions can evolve while still maintaining the historical links to instances. Say for example that a rule to diagnose asthma is updated with a new instruction, i.e. a new and more efficient way of making the diagnose. In this case it will be possible to trace which diagnoses has been made with the old version and which are done with the new, while still referring to the same concepts.

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6.3. Example based on Fass

The draft Fass report, reference 7, contains a simplified version of an information model. It identifies a few basic definitions (ten phenomena, one rule and one event). It also identifies a set of instances. The description is done at a conceptual level and not demonstrated in a running prototype. Furthermore, there is no clear link between the information model and the operational use case.

6.4. KA conclusions and recommendations

A common and open way of defining concepts within a specific knowledge area have the potential to disrupt all standardisation work performed today. If implemented and run with Subject Matter Experts in close collaboration with the standardisation and regulatory bodies, it has the potential to become a completely new and innovative method to improve and speed up todays standardisation work.

In addition, the ability to link definition to data instances and by this being able to understand the semantic meaning of all data, in all languages, for both humans and machines has the potential to revolutionise the quality of data usage and enable more advanced cognitive computing.

While the potential benefits are huge, the concept differs from existing approaches which can result in a resistance to adopt it by communities that work on interoperability, semantics and information modelling.

Knowledge Agency recommends proceeding with the following activities related to the information perspective:

- *Finalise the knowledge and information definitions in the Fass example and demonstrate it in a running prototype. Continue to work with Subject Matter Experts, not technical experts, to create definitions. Benefits must be demonstrated early in the process, such as ease of definition creation, ability to reuse definitions, ability to use linked instance etc.*
- *Identify and run scalability scenarios examining machine-assisted conflicting detection and resolution.*
- *Demonstrate the power of the solution by importing an existing data set and linking it to definitions from an existing standard and show where compliance is achieved and where there are gaps and inconsistencies.*
- *Create a white paper describing the research foundation of the meta ontology to avoid the "not invented here" syndrome.*

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7. **The technical perspective of Headroom**

This chapter describes the intended technical implementation of the Headroom solution and how it relates to existing systems. First, the various technical components are introduced, and the services and Application Programming Interfaces are described. Then different deployment and distribution options are discussed together with a set of basic Use Cases which describe some of the core functionality of the system.

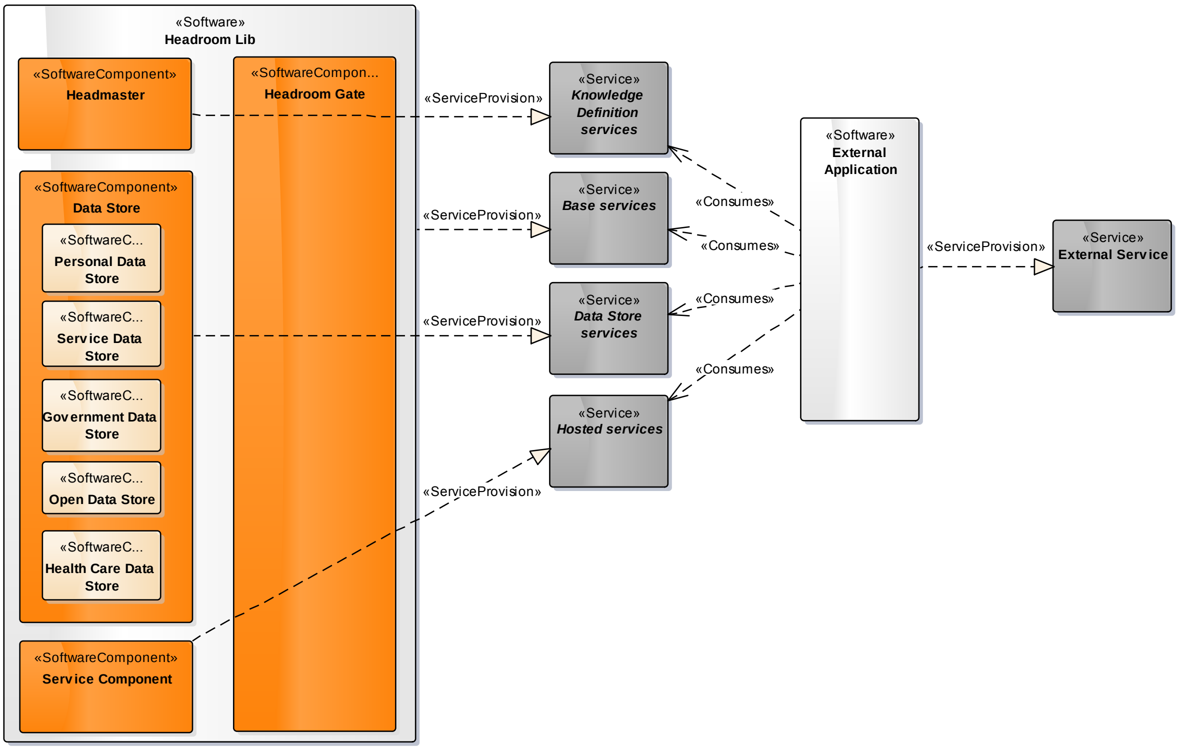
It needs to be mentioned that while the different technologies and components described in this report have been tested, there is no complete implementation available.

The main technical component in Headroom is the Headroom Lib which is a distributed software system which enables management of knowledge ontologies as well as storage and exchange of data in a secure way. The system can be installed at any type of stakeholder, including agencies, private companies and personal devices. There are multiple services and data stores provided by the Headroom Lib which allows for creation of knowledge ontologies, secure access to data, definition of access policies etc.

All data in Headroom is stored with contextual attributes, including who is the owner and what semantic definition it has. While all data in Headroom have a unique identity and location, there is an anonymous referencing mechanism in place which allows for all data to be universally referenceable, but only accessible by those that are authorised.

7.1. Components

The main technical components of the Headroom solution are described in the diagram below:



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The main component is the **Headroom Lib**, or Headroom Library. This is a software system which contains different sub-components that enables management of knowledge ontologies as well as storage and exchange of data in a secure way.

The Headroom Lib will be deployed in a distributed way so that data can be stored where the owner wish it to be stored. Naturally, there are high security requirements on this library as it potentially contains sensitive data. Data is stored in an encrypted form using keys generated by each library and all references between libraries are encrypted for each session so that they become useless without proper authorisation.

The code of the Headroom Libs is also signed, and the libs establish contact with each other in a way which makes it virtually impossible to do spoofing or man-in-the-middle attacks.

The Headroom lib is intended to be developed as Open Source code so that it can be inspected and improved by anyone and will be made available on all major technical platforms and operating systems available today.

The **Headroom Gate** component will manage all sessions between external systems and the other components in the Headroom Lib. As such it will be responsible for ensuring the integrity of the sessions with respect to Data Owners, Concepts and Services.

The **Headmaster** component provides the Knowledge Definition service which is used to define concepts and discover data instances of the concepts. The component manages templates, ensures that the concept definitions are stored and made available through various interfaces, for both machine and human consumption.

There are multiple **Data Stores** foreseen within the infrastructure that are used to store data for different purposes. Data in this case refers to instances of Phenomenon and Events that relate to definitions in the Headmaster component. The actual types of Data Stores are expected to evolve over time, but those currently identified are:

- A **Personal** Data Store used to store all private and personal data for both persons and organisations. Only the Data Owner (Person or Organisation) has the right to control all data in this store, except where laws regulate access.
- A **Service** Data Store which is limited and specific to a certain type of service. The data is stored in the Headroom infrastructure, but the service may be either external or hosted in the infrastructure.
- A **Government** Data Store which contains personal data which are by law required to be shared with government agencies. The store is hosted by the government agencies to ensure the availability of the data.
- An **Open Data** Store which is designed to store government data which is provided as Open Data according to applicable laws and regulations.
- A **Health Care** Data Store which contains data related to medical records and other information that a person might want to add to enable their care suppliers to provide them with optimum diagnosis and treatments.

The last component inside the Headroom lib is the **Service Component**. This represents a generic component developed with the purpose of processing and sharing data inside the Headroom lib and with the external applications through defined service interfaces. The Service Components are foreseen to be many and ranging very different types of applications covering many domains. They can be viewed as the "Apps" in the Headroom ecosystem and are developed by many different organisations and service providers. The Headroom operator, Origo, will act as a validator and approver of these services to ensure that they respect the rules set up by the Data Owners.

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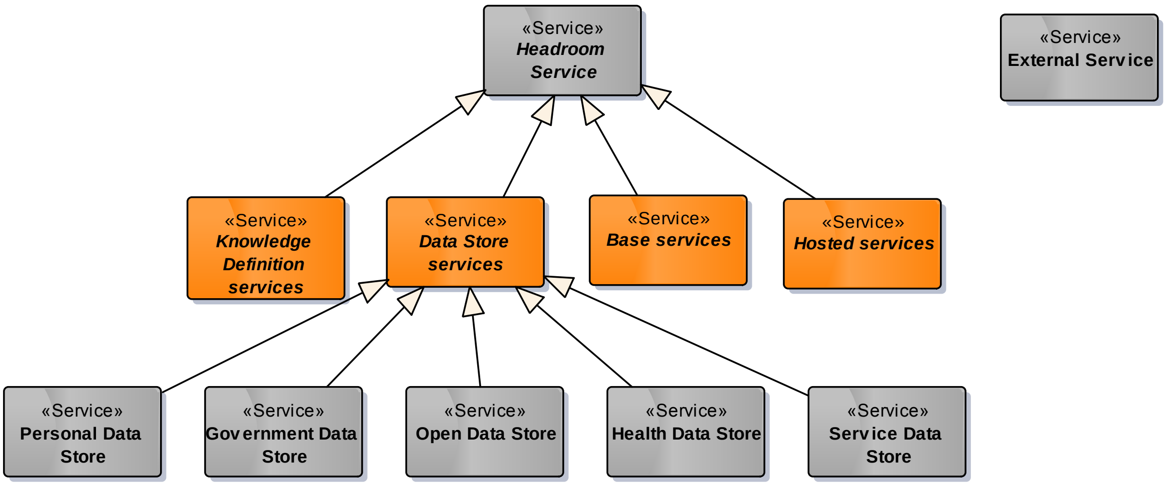
Every piece of data in Headroom and all events that changes or moves it is defined by phenomenon, events and executing functions of rules. To guarantee the integrity of data owners and that consents never can be overridden, this execution is done in the guarded part of Headroom Lib. The language to program the functions of the rule s' definitions will be made up by an instruction set, specific for this environment. The use and further development of Headroom will be the factors that drives the development of this programming language. The only requirements are to maintain the security and trust of the infrastructure and to deliver the functionality the users need for their services. The goal is to create a "programming environment" that is in close contact with the information knowledge and as non-technical as possible.

7.2. Services and APIs

Here, the services and Application Programming Interfaces of Headroom are described.

Headroom will consist of two different aspects for accessing data and services, each with their own defined entry point and mechanics for searching and finding resources. Definitions, the knowledge base, on one hand and the person's existing user roles at different services on the other.



The **Knowledge Definition** services allows for editing and viewing concepts for phenomena, rules and events and the semantic relation between them. Concepts and descriptions can be provided in any language making the definition universally comprehendible. Persons or organisations can create definitions and link them to actual data (Data instances) which are retrievable through the Data Store services.

The Knowledge Definition services are expected to have several different types of interfaces for both human and machine consumption. Many of them need to be tailored to suit a specific type of use or area of application.

While the Headroom solution promotes and encourages reuse of definitions to increase the value of data, there will be a very large amount of definitions. Hence, the Knowledge Definition Services will include features to discover definitions. The Knowledge Definition Services will also be distributed which means that there needs to be a discovery and addressing system for Definition service instances.

For anyone to work with the development of definitions the user needs to be identified and register for a user role in the Knowledge Definition service. At the same time exploring definitions and publicly available services must be open for everyone and in an anonymous way. All services will therefore be

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defined as part of the knowledge base register, which makes a service lookup and presentation natural for the knowledge base.

The **Data Store services** consist of a set of services that provides access to different kinds of data as described in chapter 7.1. Data can be created, read, updated or deleted depending on the authorisation level of the user.

The **Base services** is where basic login (authentication and authorisation) and navigation to the different services is done in Headroom. It also includes the service that delivers the total overview of all the data for a data owner, including who is the real person/organization behind the user role, what data it owns and what has happened to the data, across all services and data stores. It is also where all handling of consent can be viewed and changed. This includes data sharing contracts the data owner has in their capacity as an employee, a customer, a member and a citizen, depending on the context of the different services. Many consents will be based on free will and can be changed by the data owner, others are the expression of laws, regulation or contracts and may not be changed one by one depending on the specific relationship or contract.

Hosted services are application level services that run within the Headroom environment. They are developed by external parties but validated by the infrastructure provider Origo.

The **External Services** element is used to represent any type of service that is not provided by the Headroom infrastructure (Headroom lib).

When a user logs in, using the Base services, the infrastructure will give it options to select one of the services where the user is registered. One individual may have one or many user roles in one service and each service can be understood as an app.

The data access for each actor/owner combination is regulated by consents to limit access within the service. Without consents that technically informs about connected data in another service the infrastructure will ensure that there is no way of knowing if it exists, for anyone in this context.

In every service each user role has a "home storage point" which can be located in any Data Store provided by any Headroom lib. This means that it can be provided centrally in one location for a service or distributed in multiple locations, depending on how the service is implemented. The Headroom Libs are planned to work with distributing the needed data in a peer to peer manner between the user's closest Headroom Lib and the home storage point for each actor's and the owner's data.

7.3. Data Model

The data model in Headroom is based on two principles:

- No data can be stored without its context
- All data has a semantic meaning and definition

The above principles can be observed in the Data Model diagram below which contains three main elements:

An **Instance** is the core entity in the data model. It defines a set of common attributes that all data in the solution inherits. These attributes ensure that all data is stored with a context and includes a globally unique identifier, a date when the instance was created, who is the owner of the instance and what actor created it. All attributes except the ID and Time stamp are references to other instances. This means that if someone wants to know who the owner of an instance is, they need to look it up through an Instance Reference.

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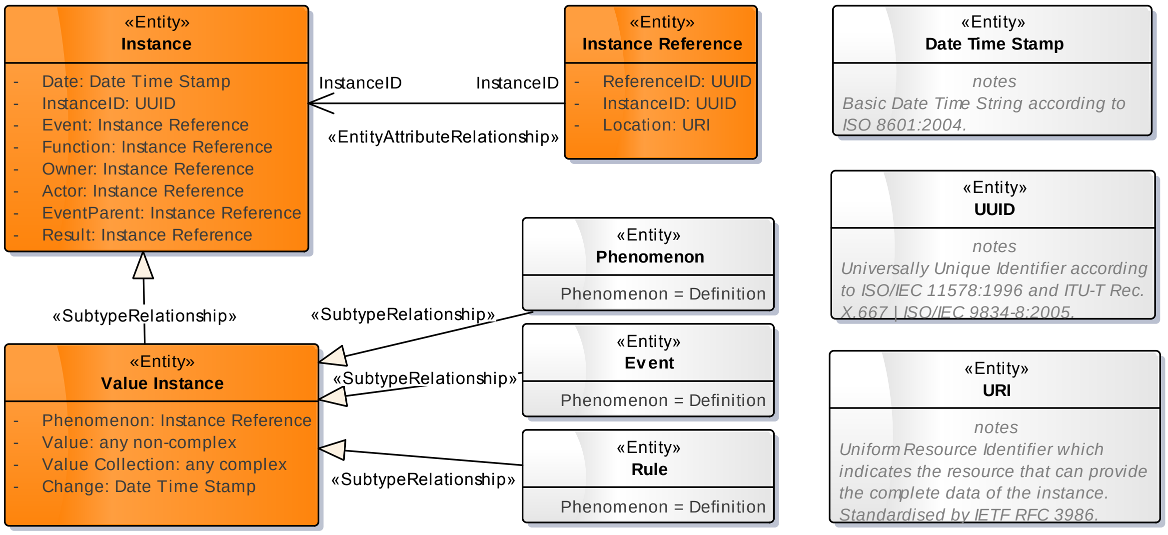
An **Instance Reference** contains a reference to an actual instance and serves as a façade for an instance making it referenceable without exposing its true identity and location. As an example, an Instance has an Owner attribute. This attribute will contain the unique identity of an Instance Reference. This is a string of numbers and characters which does not reveal anything about the identity of the owner. To see the true identity of the owner, the Instance Reference need to be looked up and opened. Naturally, this will only be possible if the user has authorisation to read the Instance containing the Owner's data.

Value Instances are those Instances that contain value data. The data can be simple, as in a string or number, or a complex composite data. Value instances always contains a reference to the type of phenomenon they are. As an example, a Value Instance with a simple value of 10 can refer to the phenomenon Kilogram. This ensures that all data always have a semantic meaning and definition.

Value Instances are also used in Headroom to define the data constructs used within the system, for example phenomena, events and rules. There is a phenomenon called (Headroom) Definition that is used for this purpose. As you can see from the diagram below, this is used to define what a phenomenon, event and rule is.



7.4. Deployment options

An important aspect of the Headroom solution is the ability to decide where storage and processing of data takes place. The Headroom architecture allows for multiple options and several factors will impact this decision such as who is the Data Owner, how important is it to prevent loss of data and how quickly does it need to be accessible.

Every piece of data or Service has a "home address", i.e. a Uniform Resource Identifier (URI) that indicates a location where data can be retrieved or manipulated. At this location, a Headroom Lib will be deployed to handle requests to the data.

The Headroom Libs are intended to be deployed at an arbitrary location in a network and at any type of organisation. As an example, a personal data store can be deployed at a location chosen by the Data Owner, like a personal server or a Origo-certified cloud service. Agencies and private companies can also host Headroom libs in their infrastructures, or in the cloud.

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While this foreseen deployment scheme fits very well with the overall needs, there is currently no complete implementation of such distributed system and there is no detailed description of how the Headroom libs are intended to discover each other or interact to ensure secure exchange of data.

7.5. KA conclusions and recommendations

The core capability of Headroom, with data always stored with its context, and always with a semantic meaning and definition makes the solution unique and with a high degree of innovation. However, the technologies required to realise the solution are available as standards and best practices already today. While relevant technologies and components have been identified and to some extent tested, no integrated solution has been demonstrated.

The Headroom Library and its different data stores is intended to be implemented in a distributed way which is necessary to avoid the need of having a central data repository. The data model fully supports this by utilising URIs to reference the location of data, but additional details are needed regarding how the Headroom Libraries will communicate with each other to share definitions and infrastructural data such as user information.

Since the purpose of Headroom is to create an open digital platform for many players, it is important that players trust the infrastructure that hosts and processes the data they own. By publishing the Open Source software code, trust and confidence will increase. However, at present, it is not explained which parts of the Headroom solution should be published as open source.

A critical success factor for Headroom will be how well it can be integrated and work together with existing systems. It must be possible to use existing data and information structures from legacy systems as starting point and it must be possible to prove semantic interoperability, information and knowledge sharing cross-organisations and improvements for the stakeholders. The Base services are critical in this respect and they will most certainly be scrutinised by many critics. The information regarding these Base services has been very limited in the study which is problematic as the confidence of the whole concept may be questioned. It has not been a showstopper for the study, but will be essential in future activities to assess the feasibility of the solution in its entirety.

The Fass example did, as planned, not contain any technical details related to the Headroom solution apart from some user experience perspectives which gave little insight to analyse the technical architecture. While this example focus on how a patient and medical doctor can use the solution, there is another user category which is important – the Concept modeller which creates knowledge definitions. To support this type of user, earlier prototypes have been developed to a fairly mature stage allowing to create and explore phenomena, events and rules. A concern regarding this prototype is how the information can be presented in a simple and comprehensible way when the number of phenomena, events and rules grow and how the system can help the Concept modeller to avoid duplications and inconsistencies.

Knowledge Agency recommends proceeding with the following activities related to the technical perspective:

- *Continue building on the Fass example and realise a technical proof of concept focusing user experience to demonstrate the benefits for medical doctors and patients. The example should include the implementation of a personal data store and how access to this is granted.*
- *Identify and develop a real-life pilot of a Hosted service where the use of anonymous data should be one of the focus areas.*
- *Further enhance the Knowledge definition service prototype to address issues of scale and user support functions. This prototype should also demonstrate how to link the knowledge definitions to data instances in external services.*

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- *Develop a clear description and a reference implementation of the Base services to increase the confidence-building for the whole concept. The description should include how they can be used by existing systems and how a data owner can work with consents to share data.*
- *Develop and demonstrate a scalable implementation of distributed Headroom Libraries which exchange data between multiple data stores in a secure way.*
- *Create a plan for which parts of the solution should be published as Open Source and which approach to use. The plan should include a time perspective which considers coordination with other development activities.*
- *Use an independent body to validate and demonstrate how the privacy by design principle has been implemented in Headroom.*

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8. Summary and proposed way forward

This chapter contains a summary of the recommendations made by Knowledge Agency and a proposed plan for how the further development of the Headroom solution can be done.

Four different workstreams are identified which can be executed more or less independently and in parallel. Three workstreams are very practical by nature including development and demonstration activities on real-life examples to achieve buy-in from the intended actors in the Headroom ecosystem. The fourth workstream is more analytical and aims at preparing for the future governance of the solution.

For all workstreams there is an overall need to expand the team to include representatives from more actors and to increase the core technical development resources.

8.1. Realise the Knowledge Definition services

This workstream address recommendations that aims at ensuring the implementation of the Knowledge Definition services. This part of the solution has much potential to provide significant benefits even if the rest of the solution would not materialise.

The main group of participants in this workstream are the Subject Matter Experts that define phenomena, rules and events in their areas of expertise. This may also include standardisation bodies and communities of interest in the areas selected for the workstream.

The following activities are proposed:

- Create a white paper describing the research foundation of the meta ontology to avoid the "not invented here" syndrome.
- Realise the Knowledge definition services and convert a limited set of existing standards to the new format to demonstrate backwards compatibility.
- Further enhance the Knowledge definition service to address issues of scale and user support functions such as machine-assisted conflicting detection and resolution.
- Demonstrate the power of the solution by importing an existing data set and linking it to definitions from an existing standard and show where compliance is achieved and where there are gaps and inconsistencies.
- Demonstrate how to link the knowledge definitions to data instances in external services.

8.2. Integrate external services and prove a scalable infrastructure

This workstream aims at ensuring that existing systems can be integrated and make use of the Headroom infrastructure. The use of external services and applications is very important as it is unlikely that all data and applications will move to the Headroom infrastructure.

The workstream also address issues of scalability and the fact that the infrastructure must be distributed across multiple types of actors.

The following activities are proposed:

- Identify applicable real-life application examples, preferably outside the health domain to ensure that the solution does not become specific to one industry.

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- Develop a clear description and a reference implementation of the Base services to increase the confidence-building for the whole concept. The description should include how they can be used by existing systems and how a data owner can work with consents to share data.
- Develop and demonstrate a scalable implementation of distributed Headroom Libraries which exchange data between multiple data stores in a secure way.

8.3. Demonstrate data sharing and consents using a hosted service

This workstream aims at ensuring that data can be shared in a trustful way once it is inside the Headroom infrastructure. As such it can be performed without major dependencies to external systems.

The use of anonymous data and giving consents to share data in the solution will be critical elements to ensure data privacy.

The following activities are proposed:

- Finalise the Fass example, focusing on Data Owners data sharing consent and how a hosted service can make use of confidential data without exposing it to the Service Consumer.
- Continue building on the Fass example and realise a technical proof of concept focusing user experience to demonstrate the benefits for medical doctors and patients. The example should include the implementation of a personal data store and how access to this is granted.
- Use an independent body to validate and demonstrate how the privacy by design principle has been implemented in Headroom.

8.4. Prepare the governance regime

The purpose of this workstream is to advance the thoughts on how Headroom can become a self-sustaining and neutral platform for information sharing.

This will have to address many critical issues related to financing, actor roles, organisational constructs as well as immaterial rights to code and certification of infrastructure providers etc.

The following activities are proposed:

- Define and describe the Headroom digital ecosystem, and from a national point of view identify actor's roles and responsibilities to find a good balance between different actors early in the process.
- Further detail the roles of the Infrastructure Governor and Infrastructure Provider, including principles for governance and the terms for the Origo trust.
- Create a plan for which parts of the solution should be published as Open Source and which approach to use. The plan should include a time perspective which considers coordination with other development activities.

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9. References

#	Reference	Version	Date	Link or reading reference
1	Headlong material Manual Headroom v1_0 Documentation and a quick guideline for Headroom v0.1.0 and Headmaster Dev. 1.0	1,0	Nov 2017	Manual Headroom v1_0.pdf
2	Headlong material An Overview paper and documentation for the Headroom concept area called Origo. Data storage and how it fits together as well as the overview of the different services like external-, Origo-, and base-services are set up and defined.	V1.5	Sep 2016	Lager av data och tjänster.pdf
3	Headlong material A high-level paper and presentation explaining why, what and how regards wicket issues and the relations between analogue and digital in a headroom and Origo conceptual perspective	V1.0	Oct 2017	Anlog-dnigital-analog.pdf
4	Headlong material A presentation and work through of the basic principles in Headmaster (multi-administrative environment for definitions). Graphical user interface walkthrough examples in the context of health care organisational set up to understand the different headmaster functions.	V1.0	Oct 2017	LifeGene allmän.pdf
5	Headlong material A graphical picture explaining a drug example in the three spheres healthcare, individual and the industry/science sphere and its unified areas where knowledge and situation awareness occurs from different user perspectives.	V1.0	Oct 2017	Tre sfärer.pdf
6	Headlong material A presentation that gives the audience a step by step walkthrough of the Headroom foundation or the tree model as follows: - Enduring information - Languages design - Information handling principles - Implementation principles. - Source-code relations towards terms and concept definitions. - From definitions to a service - Knowledge based services - Stovepipe linkages	V1.0	Oct 2017	Träddragning origo.pdf
7	Headlong material Rapport Fass Draft report from sub-project B 14 april 2018.	V0.8	April 2018	Rapport Fass.pdf
8	Headlong material Rapport Fass Draft updated report from sub-project B 21, 22 april 2018	V0.85 V0.90	April 2018	Rapport Fass.pdf

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