



Index

Summary

Purpose of this document

The Mydex Safe Secure Cloud

Modular About Me Feature Block

MAM Modules and Subsections

This is Me

Key Information

Health and Wellbeing

My Support

My Supporting Roles

Planning Ahead

The Benefits and impacts of Modular About Me

Benefit and Impact 1 Reduction or Removal of Form Filling and Duplication

Benefit and Impact 2 Seamless Service Integration enabled

Benefit and Impact 3 Personal independence, control and agency leads to empowerment

Benefit and Impact 4 Activation of personal networks of support effortlessly

Benefit and Impact 5 Improved Data Quality and reduced data sparsity

Mydex approach to enable interoperability today

The vision of common standards

Mydex Focus is on Interoperability today

Supporting Seamless Integration today

Mydex Template System the engine of interoperability today

Potential questions about the Mydex approach

Do / can Mydex support open standards?

How does Modular About Me work with Clinical and Care Records

Can organisations use the Safe Secure Cloud to underpin and power their own digital

front doors for citizens?

Can Modular About Me be used for research?

Can Al make use of Modular About Me?

Can Artificial Intelligence deliver interoperability?

Where is The Modular About Me Feature being used today?

How does Mydex Model About Me Model compare with the PRSB About Me Standard?

PRSB Implementation Approach to About Me

Could you deliver PRSB About Me as defined today as free text?







Summary

The document explains the Mydex **Modular About Me** Feature Block (MAM), its creation, and management using the **Mydex Safe Secure Cloud's** interoperability features, particularly the **Mydex Template System** and **Personal Data eXchange**.

Modular About Me enables individuals to build up a bank of detailed information about themselves that they can share safely, easily and quickly with service providers in such a way that the need for forms is eliminated or greatly reduced and service providers can safely and confidently use the data immediately.

Modular About Me during its design and development by Mydex CIC benefitted from stakeholder engagement and feedback from citizens and service providers facilitated by the Digital Health and Care Innovation Centre's Research and Innovation Programme which helped validate the range and scope of its contents alongside the PRSB About Me v1 published standard.

Modular About Me addresses one of the most commonly reported frustrations citizens have with accessing public services which is having to repeat themselves telling their story time and time again with each service provider they are referred to.

- MAM Structure: MAM is modular, containing six main modules, fifty eight subsections, and about 700 data points. These are designed to capture core information needed for effective support and self-management of health and wellbeing.
- **Control and Access:** The information within MAM is under the individual's control of the individual and is stored in their Personal Data Store within the Mydex Safe Secure Cloud. Individuals (Members) can access and share their information via the Mydex People App.
- Mydex Safe Secure Cloud: This is a shared infrastructure where individuals are at the centre, with their data under their control. Members have free for life access and use of the Safe Secure Cloud as this is the community Mydex services as an asset and mission locked community interest company who operates the Safe Secure Cloud for public benefit and sustainability as shared infrastructure.
- Organisations: who subscribe to the Safe Secure Cloud can access and update the Individual's MAM and wider event and transactional data records delivered to and stored in their Personal Data Store







- Interoperability is a core driver: MAM facilitates interoperability and data sharing between individuals and service providers through APIs and GDPR compliant Data Sharing and Service Agreements. This reduces form filling and duplication, enabling seamless service integration.
- **Impact:** MAM reduces administrative burdens, enhances service integration, empower individuals, activate support networks, and improve data quality.
- **Mydex Approach:** Focuses on interoperability in today's world working across various standards, using the Mydex Template System to configure and share data. The system supports data sharing, metadata, and various standards.
- **Comparison with PRSB About Me:** The document contrasts MAM with the PRSB About Me Standard, noting that while PRSB is primarily free text-based, MAM is structured for digital ecosystems and data sharing.
- **Potential Questions and Answers:** The document addresses questions about Mydex's support for open standards, its integration with clinical records, its use for research and AI, and how it compares to other models.

In essence, MAM is a structured, modular system within the Mydex Safe Secure Cloud that empowers individuals to control and share their personal information to improve service delivery and reduce administrative burdens.

Purpose of this document

This document is an overview of the Mydex Modular About Me Feature Block **(MAM)** and how it was created and managed using our Safe Secure Cloud core interoperability capabilities, in particular our Mydex Template System and the Personal Data eXchange.

MAM is an integrated Feature Block available via the Mydex Safe Secure Cloud

MAM as the name suggests is modular in nature with six main modules within which there fifty eight subsections and within those subsections with some 700 data points focusing specific questions and responses that themselves can be a collection of information in their own right. The six modules are listed below. Different modules and subsections can be shared with different service providers. The subsections are detailed later in the document

- 1. This is Me
- 2. Key Information
- 3. Health and Wellbeing
- 4. My Support
- 5. My Supporting Roles
- 6. Planning Ahead







These modules and subsections and the data points within them are considered by health and social care professionals as the core information needed to provide effective support for citizens at different stages of their life and to enable people and their own support networks to self manage their own health and wellbeing and identify possible routes for self directed support and information

The contents of the **MAM** are the property of the Individual which is held independently by them in their Cloud based Personal Data Store within the Mydex's Safe Secure Cloud.

This explanation of **MAM** is set in the context of the Mydex Safe Secure Cloud and how it can be used as part of integrated person centred seamless services and the many uses of this information it contains many times over by many different users.

MAM is one in a range of **integrated Feature Blocks** within the Mydex Safe Secure Cloud that work seamlessly together and support connectivity between citizens, their connected service providers and their own personal networks to create an integrated person centred ecosystem to support for them throughout their life and the events and transitions in life stages.

The Mydex Safe Secure Cloud

The Mydex Safe Secure Cloud is run for public benefit as a shared infrastructure that places individuals at the centre of their life and interactions with the world around them. The Personal Data Store is independent and under their control at all times.

Mydex CIC provides use of the Safe Secure Cloud and its services entirely free for life to any individual who signs up and becomes a Member. Mydex sees individuals as Members of the Mydex Safe Secure Cloud because they are the community Mydex as a community Interest company serve above anyone else.

Members can access their Personal Data Store at any time via the Mydex People App which is their own Digital Front Door for their life. This is provided free of charge to Members for life, just like their Personal Data Store and use of any of the SSC Services.

Members can share any and all aspects of their Modular About Me with subscribers to their Personal Data Store via the Personal Data eXchange.

All sharing and exchange is done under a GDPR compliant Data Sharing and Services Agreement directly between the subscriber and the Member.







Mydex CIC as operator of the Safe Secure Cloud (SSC) enforces that agreement automatically. Only the Member can approve a Data Sharing and Services Agreement.

Modular About Me Feature Block

The Modular About Me Feature Block enables people to reflect and express their views and wishes and information from their own perspective via responses to questions. This information is captured in a structured manner using a mixture of questions to drive capture of information and can be constantly reused so that people don't have to keep on telling the same story many times over"

The range of questions capture the answers in a variety of ways and unlike PRSB About Me the Mydex Modular About Me enables people to go beyond the current free text form filling and enables the structuring of answers in such a way as to make it portable and reusable time and time again by the Member and critically with their consent seamlessly shared with others via safe secure two way APIs under a GDPR compliant data sharing and services agreements between the Member and their service providers.

This enables seamless integration between themselves and their network of service providers' own application software systems. This is achieved via the SSC Personal Data eXchange.

This enables interoperability and portability and makes the co-management of the Members own records effortless for their friends and family, guardians acting as informal carers and their service providers across the range of public services they use provided by the public, third and independent sector powered by their rights under GDPR and the mirror obligations on organisations.

This dramatically reduces the complexity of information governance within statutory services and the web of often out of date information sharing agreements between organisations that cannot adapt to the ever changing landscape of statutory service providers and their commissioned providers and the wider network of service providers.

MAM Modules and Subsections

The Modular About Me Feature Block is structured in Modules and within those Modules subsections which contain specific collections of information most often required in an individual's interaction with the world around them. It is designed to support them throughout their lifetime and will evolve and be updated over their







lifetime.

Today there are six Modules and fifty eight subsections across those six modules (see below). Some subsections are repeated in different modules but the information only needs to be entered once. The same can be the case for specific questions appearing in different subsections. This reuse demonstrates that only the required module or subsection needs to be requested or even only specific questions within subsections.

There are approximately 700 data points within Modular About Me. New Modules can Subsections can be added incrementally as new insights and knowledge are gained about what information is required for an individual to manage their life and secure the support they need.

It is Modular for very good reasons and the use of subsections enables specific targeting of different elements of a module. This supports the different contexts and uses cases for this critical information over a person's life as life events occur and people transition between life stages. Modularity supports GDPR Data Minimisation obligations on organisation and subsections can be selected based on specific use cases and context.

Today the focus has been how the most vulnerable in society who need ongoing support are required to provide time and again a vast array of information as part of assessment for services, operational delivery of those services and reviews of services.

It is a significant amount of data points that today are currently captured many times over creating huge duplication and unnecessary administration friction, effort risk and cost.

The benefits to moving to a shared source of this information will eradicate the overwhelming majority of form filling and duplication of effort following the principle of capture once and use many times. This eradicates the microstress generated through the current siloed model which creates huge amounts of friction, effort, risk and cost for citizens, their friends and family and front line service provider teams.

Specific services who may require extensions for the specialised information needs can configure their own templates to support referrals or service delivery. The data collected is stored in the individual's personal data store for reuse.







Readers should remember this represents a human lifetime and Modular About Me will build up over time based on need or can be populated and curated at any time by themselves, their service providers for co-managed care and those who support them who have access to the individual's information via delegated access in Member controlled person networks we call Circles of Support.

The Modules and Subsections are listed below

This is Me

- Personal Details
- Contact Details
- Current Support
- Personal Qualities
- My people
- Pastimes
- Home
- Routines
- Reminiscence Gallery
- Money Matters

Key Information

- Medical Details
- Medications
- Main Support
- Access
- Priorities
- Support Package
- Preferences

Health and Wellbeing

- Medical History
- Wellbeing
- Memory
- Staying Safe
- What is important to Me
- Money matters

My Support

- Communication
- Medications
- General fitness
- Practical help
- Moving around inside
- Moving around outside
- Getting Washed
- Foot Care
- Personal aids
- Continence
- Eating & Drinking
- Bedtime
- Falls
- Digital
- Support Package
- Action List

My Supporting Roles

- Personal Details
- The People I care for
- My Caring role
- Impact on my health
- Emotional Wellbeing
- Impact on my finances
- My Life Balance
- Impact on future plans
- Impact on employment
- Impact on my home
- Other aspects of life
- Skills & Experience
- What Matters

Planning Ahead







- Attitude to Change
- Power of Attorney
- Anticipatory Care Plan
- Will
- Unpaid Carer
- Advanced Directives

Modular About Me is configured using the Mydex Template System which is core to interoperability and is just one representation of the data stored in an individual's Personal Data Store. Please see more on the Mydex Template System later in this document. The Technical documentation for Modular About Me is used as an example of the capabilities of the Personal Data eXchange's Mydex Template System and can be found on our publicly available technical documentation site.

The Benefits and impacts of Modular About Me

The positive impact of Modular about me is significant across many dimensions for all stakeholders especially citizens and their friends and family and services providers. It eradicates the core systemic issues hampering the delivery of almost all public service organisations efforts at person centred strategy implementation. Because they are organisation centred, these lead to low productivity, duplication of effort and significant friction, effort, risk and cost that leads to poor experience, delays, outcomes and exclusion.

Benefit and Impact 1 Reduction or Removal of Form Filling and Duplication

Members having their own MAM significantly reduces the amount of form filling and duplication of effort that exists in today's current approach to accessing public services. Forms come in a mixture of formats such as MS Word, PDFs, Online Forms of one form or another. The core principle is capture once and use or share many times. It also becomes easy to maintain and may be built up over time as needs arise.

MAM eradicates the need for forms which creates exponential benefits for the individual, their friends and family and their network of service providers.

The forms MAM eradicates broadly ask a common or core set of questions and often service specific questions. These forms are often laid out differently and questions may be worded slightly differently.







Almost universally these forms use organisation centric language which can often seem invasive, asking for too much information without explanation or they are impersonal, especially when an individual has answered these questions many times over for other service providers.

Forms are a significant element of microstress buildup and can lead to errors and omissions for a wide range of reasons which leads to delays in accessing services.

These manually populated forms often lack structure in terms of the information captured relying heavily on free text or tick boxes. Service Providers processing these forms then have to transpose these forms into their own application software systems which seek to structure information.

This creates a significant administrative overhead and can compound errors and delays in access to services or the configuration of services. This administrative work is often done by front line service delivery teams and can delay their ability to engage with the configuration of services and reduces the time available to engage with the service user who completed the form.

Forms are holding back productivity and reducing capacity of front line teams and creating a poor service user experience. It is one of the biggest barriers to delivering the almost universally stated person centred services that are joined up and easy for citizens to access and use.

When a Member's MAM or specific Modules and Subsections of it are shared with Subscribers the responses to these questions can be shared seamlessly and presented with subscriber centric question format so it is familiar to subscribers' front line teams or researchers which view the information as relating to an individual and are phrased in their familiar questions formats and language.

The contents of MAM can be seamlessly integrated into Service Provider' own applications they use to manage service delivery, improve data quality, reduce errors and the sparsity of data. This feeds into upstream management and statutory and regulator reporting and compliance requirements.

MAM is designed to eradicate the need for paper forms, documents such as MS word and PDF forms as well as forms presented on websites and their manual processing.







It follows the core principle of capture once, use many times and is persistently stored by the individual for their life and ready for seamless two way data sharing to enable citizens to be connected to their own ecosystem or web of service providers and their own personal support networks.

Using MAM eradicates or reduces significantly the Friction, Effort, Risk and Cost (FERC) of records management and time and effort of interactions with third parties by enabling reuse of previously captured information on a selective basis set in the context of a specific service or third parties information needs all managed effortlessly under a GDPR compliant Data Sharing and Services Agreement with defined use cases.

Benefit and Impact 2 Seamless Service Integration enabled

Enabling seamless service integration within an organisation across their different, often siloed systems is made possible efficiently using our Mydex Template System and common APIs which makes it possible for each application to simply connect once to the Mydex Safe Secure Cloud.

This is equally true for any organisation and delivers the step change in seamless service integration across a network of service providers who serve and support the same citizens. We call these clusters, united by a common service catalogue and the use of multi-disciplinary teams each potentially using different applications or none at all. We enable any organisation to get connected using what they have today and can assist them to connect to the SSC.

We eradicate the highly expensive organisation to organisation application to application integration which is too expensive and almost impossible to maintain as different software vendors develop and extend their own applications or cease to exist. The economics of point to point integration does not make any sense.

Enabling each application to plug in once to a common shared infrastructure (the Safe Secure Cloud) with the individual at the centre that can manage the interoperability seamlessly can deliver seamless service integration that is affordable and maintainable over the long term. It delivers significant reductions in operational service delivery costs and boosts productivity and the timeliness and quality of outcomes.

Benefit and Impact 3 Personal independence, control and agency leads to empowerment

Central to our architecture is ensuring our Members have independence at all times for the personal data about their lives and the events and activities recorded in data about







their life.

In reality only an individual wants or needs a true 360 degree of the totality of their life, most organisations have a specific focus set in the context of what they do as an organisation e.g. services, analysis and research for many different purposes.

By ensuring independence for our Members we make it possible to apply control over how, where and when their life data is used in line with their needs, wants and interests.

We provide our Members with the agency to use their own data and share their life data to connect with organisations, communities and each other based on their needs to reduce the friction, effort, risk and cost they experience in their life and enable them to gain a sense of coherence and empowerment from the independence, control an agency they enjoy.

Members can effortlessly access services, contribute to things they are interested in and want to support certain in the knowledge they are in control and not locked in or excluded. They gain a better experience, faster, safer and more effective outcomes for themselves and their family and friends

Benefit and Impact 4 Activation of personal networks of support effortlessly

Members and their Service Provider Organisations also gain access to the individual's own personal networks of friends and family, households who may be acting as informal carers and providing ongoing support to the Member.

The Member can create, activate and integrate their own personal networks through another Feature Block called Circles which connects them into their life and the network of service providers who support them.

The Member is always in control about what level of access and delegated authority they assign. This is managed through their own People App provided free for life by Mydex which is pre-integrated to the Safe Secure Cloud. All members of their circles are automatically provisioned free for life their own People App, Digital ID, Personal Data Store and connectivity across the Safe Secure Cloud

This removes the complexity of information governance and ensures each organisation can transparently interact with authorised informal carers and bring them into the service users journey with confidence without any concerns of safeguarding, data protection as the individual is in control of what access they have.







Benefit and Impact 5 Improved Data Quality and reduced data sparsity

By enabling two way data sharing between the individual and the automatic distribution and ongoing maintenance of an individual's own core records within the Personal Data Store all stakeholders will see a rising tide of improved data quality and a reduction in the sparsity of citizens records across their network of service providers which will improve the quality of services and improve productivity and effectiveness of services.

It will also dramatically reduce the time it takes to generate management reports that help manage and plan services and prioritise investment and deployment of resources based on accurate operational service interaction data and caseload.

This will dramatically improve statutory and regulatory reporting and feedback loops to policy and strategy execution and implementation dashboards and enable them to be more responsive and timely in their reporting.

Mydex approach to enable interoperability today

Mydex Modular About Me (MAM) has implemented the principles of PRSB but implemented for a digital ecosystem and network of service providers who wish to create seamless service integration and reduction in the duplication of effort through two way data sharing and maximises the ability to reuse its content across a person's whole life.

MAM is designed to support the full spectrum of a person's life and works seamlessly with other person centred Feature Blocks to support the end to end delivery and use of services and can be configured to meet a wide range of contexts and use cases.

The Mydex Modular About me enables individuals to have a continuing dialogue with themselves from a personal perspective beyond the context of a life event, transition between life stages and is designed to make it easier to maintain their own life records for their own personal use and between themselves and those who provide support to them whether this is friends and family, informal carers and supporters and service providers across the public, third and private sector.







The vision of common standards

We recognised a long while ago the drive towards common standards is a global endeavour and there are many competing standards Development Organisations often with overlapping agendas and standards. It can often feel like a standards war with deeply held beliefs and agendas by those who work on them, driven by their own vision and focus areas.

We recognised that common standards may take many decades to materialise and be adopted and may never be achieved universally or globally across the entirety of a person's life, which is our dominant focus as a mission driven community interest company supporting our Members throughout their life.

Standardisation is further complicated by the domain boundaries being set on Standards work such as health and social care which has many competing standards and architectures that are not interoperable directly.

Mydex Focus is on Interoperability today

Our focus is on Interoperability across proprietary and open standards today because that is the crux of the matter for a safe, secure digital economy and the range of ecosystems of which there are many across the UK and the rest of the world and it is what our Members and Subscribers need.

The need for Interoperability today has informed the design of the Safe Secure Cloud that places individuals at the centre. Our Personal Data eXchange is an interoperability engine for people and organisations making it possible for personal data and events to be shared seamlessly, securely and in a trustworthy manner across a person's life.

We are doing the same with our Identity Services to allow individuals to integrate the different digital identity ecosystems that they have to use so they can manage them and join them together for their own benefit.







We are also working to solve interoperability for non personal data using our Master Reference Data Services so that different classification systems, curated content and directory services can be seamlessly integrated for the benefit of our Members and our subscribers and reduce the complexity and cost for application software developers and services that require different forms of classifications based on the ecosystems they work within.

Supporting Seamless Integration today

To deliver the promise of seamless services integration we have created the means for application software developers selling applications and solutions to organisations to plug in easily and enable two way data exchange of personal data and events as well as interoperability across classification systems they are required to support by their customers in different parts of the world.

The same applies to application software developers delivering apps and services to citizens to bring their own data into these applications and secure the value offered by these applications across their life for any purpose, safe in the knowledge that their data is under their control and protected from misuse as it is shared and used under a GDPR compliant Data Sharing and Services Agreement.

A Data Sharing and Services Agreement that they approve and enables them to maintain their independence and pick and choose what applications they use over the life without the loss of control and makes migration between these applications easy and effortless.

The interoperability approach centred on the individual reduces the risks of fraud and harm including identity theft and adds a new layer of trust to the digital economy and an independent personal data infrastructure that anyone can use and access just like other forms of infrastructure.







Mydex Template System the engine of interoperability today

Modular About Me is just one example of Mydex Template System designed to ensure interoperability between diverse subscriber needs and applications by integrating our Members Personal Data Store via the Personal Data eXchange which provides our Members with connectivity and interoperability with the outside world. The Personal Data eXchange supports two way data and event sharing and engagement across their own personal networks and demonstrates what a person centred human rights based approach can deliver to boost productivity, seamless integration..

Templates can be configured using data from the personal data store. The Mydex Template System has a Directory of Questions which means those questions can be added to the template alongside other structured data and collections of data and be integrated into the structure of the Template.

Templates can operate a single level or be broken down into Modules and subsections with collections of data.

Different templates can use existing modules from other templates and different subsections and sub-level nested components that can build collections of specific records that are needed and hold present those records in different contexts enabling maximum reuse and no duplication of data.

Templates can be considered Graphs, a popular term in analytics driven use cases, message templates for data exchange based on different standards. The key point is data and events and the context of those events and data are stored once and once only.

The Mydex Feature Blocks and Templates manage the filing and storage of all data in the PDS over an individual's whole life and supports the core principle of many uses by many users.

Templates can be configured to support any specific standard where required and adopted within an ecosystem or can be configured to support a proprietary standard where no open standards are available.







Templates not only carry data they also carry the meta data such as the headings, labels, guidance notes relating to the content and any validation requirements. This can be used by Subscribers to speed up and dynamically populate their own applications experience layer of their own applications or it can switch off different aspects of the meta data if the only requirement is a structured payload of data.

Mydex CIC uses the meta data layer within its own web applications we provide to our Members and those web applications we provide to our Subscribers. All Mydex SSC Web applications follow the person centred model and make use of our three core API services and Feature Blocks.

Mydex Web Applications are extremely efficient and secure because they do not hold any personal data themselves as they make use of the Personal Data Store, Master Reference Data Services and Identity Services which streamlines information governance, reduces cyber security risks.

This means subscribers are not acting as the data controller directly as the data is in the individual's own personal data store and is encrypted in storage and transit uniquely further protecting for cyber attacks and avoiding the risks of ransomware attacks and data breaches

Mydex publishes openly all the Safe Secure Cloud Feature Blocks API endpoints and all Templates created using the Mydex Template system.

Our number one goal is to reduce the time and effort of plugging into the Safe Secured Cloud to ensure our Members have access to and use of all their personal data and the events around their life and can use it for their own purposes and share it when and where they need with subscribers under a GDPR compliant Data Sharing and Services Agreement.

This is where true interoperability comes from today







Potential questions about the Mydex approach

Do / can Mydex support open standards?

Yes of course, we do today and we can do more when needed by configuring a template to meet the standard using the Mydex Template System.

We are constantly tracking not only the development of open standards but their adoption rate which is a core part of our mission as a community interest company. We are members of the OpenID Foundation, the Open Wallet Foundation, MyData Global and review and contribute to the development of open standards

We believe the development of and adoption of open standards will take many decades and its adoption will not be universal hence the need for our Interoperability engine.

How does Modular About Me work with Clinical and Care Records

Extremely well, they compliment each other. MAM provides a personal source of truth that is well maintained and consistent across a person's interactions with health and social care. If the clinical and care sources of truth are available and integrated into a Members Personal Data Store they can be compared and contrast with the individual's personal records and where appropriate be updated to reflect a shared understanding.

This will increase the overall value of the information across the network of service providers and dramatically reduce the need for physical paper based communications, electronic documents such as PDFs, Word Documents and be replaced with digital structured documents that can be integrated into a person's life records to increase the range of data including statutory records of medications, health conditions, diagnoses, test results and other forms of measurements.

Critically this puts the individual at the centre and can share information directly across the wider care network across the Third and independent Sector and bring new insights and information back to statutory public service providers and commissioners which will enhance service delivery productivity, management reporting and statutory and regulatory compliance reporting.







Can organisations use the Safe Secure Cloud to underpin and power their own digital front doors for citizens?

Yes, of course. Organisations can connect their websites, portals and digital front doors and apps directly to the Safe Secure Cloud make potential service users have a better experience and personalise that experience and reduce the friction effort risk and cost involved in starting a new journey with an organisations and support repeated use of because the history of that use can be stored in their Personal Data Store.

Depending on the scope and ambition of such websites and apps new assessments can be completed in real-time drawing on the citizens personal data store to feed and help configure experience and defined assessment pathways effortlessly without the need to fill out forms. The organisation can define their own process flows and the specific data requirements at each stage of that flow. This could be as simple as a self directed referral through the automatic completion of an assessment and its outcome and move seamlessly to onboarding and activation of service.

These websites and apps simply need to be able to connect to the Safe Secure Cloud Core APIS they need, especially the Personal Data eXchange and potentially the Master Reference Data Services for seamless integration of directories and curated content. If desired the identity services can orchestrate existing third party identities and link them to the Members core digital identity.

Any activity or information entered during use of the connected website, app or service is stored in the individual's Personal Data Store and is available for viewing, use and updating via the Members independent People App and seen in the context of their whole life and can be managed from that point onwards for operational service use.

That same information is now available for reuse with other service providers and the countless websites and digital front doors and apps organisations present to citizens to showcase their services and capability. They only need to connect once to the Safe Secure Cloud.







Can Modular About Me be used for research?

Yes of course with the Members consent.

We are already seeing the emergence of the next generation of Trusted Research Environments that need structured data to feed into the development of algorithms as well as large language models for the development Generative AI and workflow automations as well as more detailed insight and analysis of the state of population level health and care analysis and planning as well as the need to cross reference this to the wider social determinants of health and wellbeing.

New privacy enhancing technology and pseudo anonymous identifiers are enabling ongoing longitudinal studies that can follow an individual across their life journey without identifying them directly. Our identity services are enabling pseudo anonymisation as an integral part of creating personal data pipelines that can feed into these environments. Our Research Dashboard enables researchers to build their research datasets directly from the contents of a personal data store and apply privacy protection by masking personally identifiable data automatically.

The benefits of personal data pipelines and our pseudo anonymisation capability is a greater agility in terms of undertaking research and tuning as it evolves and undertaking analysis over time to see how circumstances and outcomes are changing in a person's life.

Access to personal data that is privacy protected is essential to enable personalisation and configuration at scale of advice and services and self guided decisions without exposing their identity to third parties but letting people benefit from personalised services and advice whilst remaining independent and in control at all times.

Modular About Me is only one part of the picture it is often the events and transactions and behaviours of individuals over their life across various aspects of life that can transform research and this is now possible directly through subscribing directly to an individual's personal data store through the personal data exchange and the pseudo anonymisation services







Can AI make use of Modular About Me?

Yes absolutely, it actually delivers the rich data needed to assist AI in configuring its knowledge based to respond to the individual's circumstances. Of course AI is only as good as the large language models behind it which require careful building using curated content and knowledge of domain experts and the essential guard rails to ensure it does not harm. Structured Data in Modular About Me will reduce the amounts of questions an AI might ask and could speed up risk stratification, assessments and the nature and type of recommendations it makes

Can Artificial Intelligence deliver interoperability?

Artificial Intelligence is currently quite good at analysing the conflicts and overlaps between open standards and the potential underlying causes of lack of interoperability. But this requires access to the open standards and proprietary standards and protocols used to undertake that analysis.

Artificial Intelligence will be helpful in answering questions and analysing structured data and free text data but the automatic interoperability between two different data standards in real time as part of a digital ecosystem would be problematic if it does not have rigorous mapping table or use of specific templates to undertake a reliable mapping and ensure seamless interoperability.

And of course Artificial Intelligence regulators and standards bodies are seeking to ensure interoperability across commercial and open source large language models and AI services but we are in the foothills of that as commercial organisations seek to capture market scale and differentiation interoperability is seen as a secondary objective to growth and market capture.

Where is The Modular About Me Feature being used today?

The Modular About Me Feature Block and the Mydex Safe Secure Cloud is being used across Scotland as part of the Digital Health and Care Research and Innovation Programme which involves a range of Live Pilots with real citizens and Service Providers.

The Safe Secure Cloud and MAM are being used in a National Digital Front Door Pathfinder project called Community Connections which is being piloted within a number of DHI projects.







Community Connections is seamlessly integrated to the Mydex Safe Secure Cloud for Personal Data eXchange, use of Mydex Master Reference Data Services and the Mydex Identity Federation for single sign on and orchestration services using two third party identity providers for citizens using Public Services in Scotland.

Current DHI projects are within Moray, Edinburgh, Lanarkshire, Abderdeen.

The Safe Secure Cloud has provided the foundational infrastructure for these projects and it is also being used as part of the Macmillan MyData Store pilot operating on two of the nine Improving cancer journeys in Scotland in West Dunbartonshire and Glasgow.

A sandbox version of the Safe Secure Cloud is being used within the Data For Children Collaborative Infoshare Project as as part of the Promise programme looking to unlock the potential of data sharing to support care experienced people in Scotland

New clusters are forming within Scotland and in England that seek to harness the power of the Safe Secure Cloud including the adoption of it to connect the third and independent care sectors and social housing together to deliver seamless services and work more effectively with Statutory Services and their commissioners

How does Mydex Model About Me Model compare with the PRSB About Me Standard?

The <u>PRSB About Me Standard</u> is the product of collaborative working by health and care professionals and is considered to be the most important detail that a person may want or need to share with professionals in health and social care.

This information might include how best to communicate with the person, how to help them feel at ease or details about how they like to take their medication. This standard outlines how About Me information should be documented and shared in health and care records.

PRSB Standard is principally a series of questions with free text answers with some coding of records using SNOWMED-CT for clinical records and ongoing analysis and tracking as part of public health and planning.

PRSB Implementation Approach to About Me

PRSB states in their implementation guidance that the expectation is that this information would be **written** or **recorded by an individual**, supported by a **professional or carer** (or by someone on behalf of the person if they do not have capacity).







It includes options to use multimedia files which are particularly useful when a person has difficulties expressing themselves, or for showing how to do things or actions and reactions.

It is recommended that About Me information is reviewed and updated at key transition points for example for children and young people with Education, Health and Care (EHC) plans when transitioning from primary to secondary school, moving onto college and whenever their home circumstances change (for example moving into supported living or residential care). The transition process from children's social care to adult social care is also a recommended time for reviewing and updating About Me information. For adults, it should be reviewed and updated at planned reviews or when circumstances change.

It should be possible for the individual to update their information whenever they want or need to.

It is recommended the individual (or the person supporting them to write the information) is prompted to consider:

- that the most important information comes first in any section.
- avoiding adding too much information as important information may be buried within text making it difficult for the professionals to easily digest the information and use it to personalise care.
- when the use of multimedia is effective and ensure that videos are kept short.
- that they do not need to put information about themselves in every section, only where they feel they have information they want to share.
- the sections enable the individual to record whatever is most important to them and therefore are broad and few in number. Local implementers could decide to structure the information within the sub-categories further.

PRSB About Me elements are free text to allow the person to elaborate on their preferences (e.g. what matters to them). To help individuals to structure their information within the sections a set of possible prompt questions have been included with this guidance, but please note that these are intended as a guide and should not constrain a person's responses to the sections in About Me. If implementers are working with a particular cohort, they may wish to consult guidance from relevant bodies or charities and tailor the prompt questions accordingly.

PRSB About is an excellent piece of work and has clearly been informed through the analysis of countless Forms of all types used across health and social care.







PRSB however has not been technically decomposed for structured data or the seamless sharing and integration of records across an ecosystem of organisations using a diverse range of software applications which hold structured records.

PRSB About Me is only a part of the information requirements that lead to provision and delivery of services. This includes an extensive range of events and transactions and specialist additional information. It is also focused on specific touch points during a person's life such as periods of transition where two way interactions and additional information is required.

Could you deliver PRSB About Me as defined today as free text?

Yes of course we could configure a template to support PRSB About Me, this would involve retrieving the required information from the Personal Data Store and converting structured data to largely free text if this was required.

Given our mission and focus we personally would struggle to understand how that would help people or service providers deliver seamless integrated services but it may be beneficial for traditional researchers who want to mine free text using machine learning to create analysis of the free text with links to the specific classification codes used to identify specific health conditions, diagnosis and event contexts.

