

Request for Information (RFI) on Advancing Privacy Enhancing Technologies

World Data Exchange

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LEADING THE WORLD IN PERSONAL DATA CONTROL AND PRIVACY

RFI Response

Advancing Privacy-Enhancing Technology

Submission for the US Office of Science and Technology Policy (OSTP)

World Data Exchange Holdings Pty Ltd

8TH JULY 2022

Disclaimer – the views expressed in this submission have been provided in good faith and are based on our own beliefs and industry knowledge which is subject to change without notice due to the rapid evolution of the Data Economy, legislation, and world events. E.&.O. E

Office of Science Technology Policy (OSTP)

Submission emailed to | to PETS-RFI@nitrd.gov

July 8th, 2022

Advancing Privacy-Enhancing Technologies

World Data Exchange (WDX) is an innovative private Company offering consumer-centric personal data sharing technology infrastructure with embedded Privacy, Security and Consent functionality that places the individual at the centre of their data controls.

As an industry stakeholder in Human centred data sharing innovation we welcome the opportunity to comment on advancing Privacy-Enhancing Technologies (PETs) for the consideration of the White House Office of Science Technology Policy on behalf of the Fast Track Action Committee on Advancing Privacy-Preserving Data Sharing and Analytics of the Subcommittee on Networking and Information Technology Research and Development (NITRD) of the National Science and Technology Council, the National Artificial Intelligence Initiative Office, and the NITRD National Coordination Office.

Whereas we believe industry, academic advocacy, and public commentary are vital to assist Government on informed development of a national strategy on privacy-preserving data sharing and analytics, along with associated policy initiatives.

We support National strategy which seeks to put forth increased vision about the responsibly of harnessing privacy-preserving data sharing and analytics to benefit individuals and society. We recognise the aligned purpose to propose actions from research investments to training and education initiatives, to the development of cohesive standards, policy, and regulations needed to achieve that vision, in a manner that advances current Privacy Regulations and promotes data protections for all, as part of a comprehensive regulatory approach towards digital democracy to which Privacy Enhancing Technology will play a key role.

About us

World Data Exchange is a Sydney based Australian company established to introduce a range of privacy enhancing technologies (PETs) and digital rights management solutions empowering consumers to protect and mobilise their data for their benefit. Our technologies provide consumers with the means to control and manage their data using methods such as tokenised consent certificates and decentralised (self-controlled/ encrypted) data wallets as well as assisting connected businesses to transact permissioned data sharing in a compliant “privacy by design” manner.

WDX is committed to the adoption of ethical consent management and related security frameworks that provide an interoperable and consumer-centric approach to personal data

sharing in a digital environment. As an emerging industry leader our team is happy to discuss any of the issues covered in our submission in further detail upon request by OSTP.

PETs by way of data facilitation platforms

The digi.me personal data exchange platform from WDX offers infrastructure specifically designed to enable individuals to securely regain and self-aggregate, view and exchange their personal information from multiple sources. Then with their consent, to decide how it may be shared with others.

The digi.me PET technology is classified as an intermediated dual sided infrastructure Platform/App marketplace designed to;

- provide individuals with the means by which they can connect, access and keep their personal information up to date in real time from multiple different data sources
- link to multiple data sources via Apps, web-based services, and other structured and unstructured databases through Application Programming Interfaces (APIs)
- enable people to securely download their personal information and to store it in a device or other cloud storage location of their choosing, with the entire process safeguarded using strong encryption
- enable individuals to understand better the nature, extent, and value of their personal information through a dashboard that provides both a visual representation of it as well as curating it so that people can 'make sense' of their own data holdings
- provide individuals with functionality that easily empowers them to share their personal information safely if they choose to do so on the terms that they determine

digi.me does not see, touch or hold user data



Data encryption and normalization happens inside the app without **digi.me** ever being able to see or access user data.



Only the user has the credentials to access their **digi.me** library and must provide credentials directly to data sources.



digi.me stores no user data. The user chooses their own location where encrypted data is stored.

Our privacy by design and distributed architecture reduce costs & liability

In short, it is a platform rich in privacy preserving technology (PPT) that gives people awareness of, and control over, their personal information.

The digi.me platform uses an innovative decentralised architecture approach to implement multi-sectoral data facilitation routing. This means that at no time does digi.me touch, hold

or see its users' data. The digi.me platform does not sell or trade user data. It does not tell its users how or where to share their data. The platform provides the data pipes between individuals and the holder of their data and those to whom they wish to share their data in a way that is private and secure.

As a private and secure data exchange platform, digi.me enables **data portability**; complies with the requirements of the European Union's (EU's) *General Data Protection Regulation* (GDPR) and has been subject to an EU data protection impact assessment (DPIA). To satisfy EU and other international privacy requirements, it adopts a 'Privacy by Design' approach to protecting personal information. digi.me also meets or exceeds international security standards.

Digi.me functionalities are flexible and scalable. They are not limited to any categories or to industry or social sectors. Currently, they include health, finance, social, wearables and entertainment.

Input on the current privacy regulation environment

Alongside members of organisations such as the [MyData Global](#) forum, and a multiplicity of other organisations providing PPTs or privacy enhancing technologies (PETs), World Data Exchange recognise that individuals' views on privacy may vary widely, depending upon the presence or absence of trust, their degree of knowledge about privacy issues and risks, their ability to protect their privacy (technical 'know how'), and whether or not they obtain a benefit or advantage from disclosing their information.

In short, there is no one-size-fits-all approach to privacy, with individuals changing their views over time, between organisations, and in accordance with their preferences or personal beliefs. This spectrum of views produces demand for a range of technical solutions, including new or enhanced ways of managing consent.

Currently, it is difficult for individuals to have a clear view of the way in which their information is collected, used, disclosed, stored, and otherwise handled despite the fact that privacy legislation is pervasive and technical solutions exist for a range of privacy issues and risks. Currently, there is a limit to any individual's ability to manage all relevant privacy issues and risks on their own. We believe that it is important not to underestimate the number of people who would like to adopt more privacy-aware data practices but do not have the knowledge or technical ability to do so. Privacy regulators, backed by appropriate legislative frameworks, can help individuals take steps to protect themselves and develop greater trust in the online environment.

Increasing concerns around transparency and fairness, as well as a renewed interest in ethics, are a direct response to increasing complexity, monetisation, and opacity in the personal information ecosystem. We are seeing regulators around the world questioning whether or not the approach to personal data taken by large digital platforms is lawful and fair. We are seeing governments around the world taking another look at their privacy legislation, asking whether or not it remains fit-for-purpose and making changes in response. In addition to the EU, this has included the UK, Brazil, New Zealand, Singapore,

California, and Canada. Previously ‘dormant’ legal policy issues – such as online tracking, surveillance and dark patterns – have become dominant.

Almost continuous data breaches, as well as the impact of the GDPR and Californian privacy legislation, have also contributed to a commercial shift away from the non-transparent collection and handling of personal information, towards more consumer-centric approaches. Multiple market responses are emerging to address these concerns. Whether this involves established players like Google changing their practices or Apple mandating pro-privacy requirements – or newer, ‘privacy first’ companies like World Data Exchange developing innovative platforms, products, and services – significant change is underway.

This activity demonstrates that PPTs and PETs are continuing to develop and evolve in response to privacy-intrusive products and services. In the mid-1990s, [Privacy by Design](#), along with its 7 Foundational Principles, emerged in response to Pets’ inability to gain traction. Almost 25 years later, in 2022, PPTs and PETs are no longer untested or failing to gain traction – they provide a component of an overarching privacy solution, alongside legislation, regulation, organisational practices and Privacy by Design or privacy engineering approaches. Any updates to the Privacy Act should be informed by these developments while maintaining the current principles-based and technology neutral approach.

Key input on forming Privacy Policy

- We support the evolution of Privacy Policy in review by several Governments and welcome any regulatory led changes or enhancements to that enable it to remain up-to-date and meaningful, capable of tackling the specific privacy issues and risks facing us today
- We note the importance that Policies within such Regulation remaining technology neutral. In particular privacy legislation:
 - Policy should not impede the development of multiple technical solutions, reflecting the multiplicity of individual views on privacy; and
 - Policy should not prevent businesses from offering PPTs/PETs as part of, or the primary component of, their commercial offerings
- The Privacy policies should maximise consistency in its operation, including through the removal of unnecessary exemptions that result in increased uncertainty for individuals and organisations
- Recognising that consistency remains key to streamlining international privacy compliance requirements, Governments just like in our home Country of Australia should continue working towards a global standard of privacy protection, thereby enabling a small technology business to operate through compatible platforms and standards designed for global reach and cross border frameworks. Likewise, it is important that Governments and Business provides clients/citizens with equivalent protection when travelling with cohesive jurisdictional regulations – this point,

rather than ‘adequacy’, should provide the policy basis for pursuing consistency on both a National and International levels

- There is an increasing need to separate out issues relating to ‘consent’ within policy principles, ‘consent’ within an entity’s Terms and Conditions, and what may prove to be the ‘death throes’ of consent-based cookies and related tracking technologies. Each of these involves different legal, regulatory and policy issues. They should not be conflated. A failure to separate out the various definitional, policy and legal/regulatory issues relating to consent is likely to result in further confusion and, potentially, lead to reforms that prove to be undesirable in the medium-to-long term
- Claims around ‘consent fatigue’ in media we believe are vastly overstated and avoid tackling the real issues faced by individuals. This aspect within Privacy Policy requires further, detailed contextual analysis. We note that numerous technical, regulatory, and operational options are available now and can be used by entities and individual consumers to streamline consent processes. The key focus here should be protecting the individual’s autonomy
- There are two core elements from the GDPR that we suggest should be considered as part of the US Privacy policy reforms processes which seek to include PETs
 1. A straightforward right to data portability that is consumer-centric and enables all entities to participate subject to meeting a minimum set of technical requirements (ensuring data portability is viewed first and foremost as an individual right)
 2. Explicit and informed consent (supplemented by the regulator as/if required) to ensure that individuals are protected from online tracking, surveillance, and dark patterns (amongst other current issues)

Industry focus | PETs and Patient Centric Healthcare

eHealth as an “in focus” industry sector presents the opportunity to propose significant step change by utilising PETs through emerging Patient Centric health models staging the entrée towards the future of digital health-care services.

Patient Centricity becoming “the new normal” fundamentally transforms the health industry’s ability to provide and lead cohesive digital transformation through enabling platforms which unite and underpin the eHealth sector across our wider eco-system via the critical element of secure, private, and interoperable data (as a raw material) delivered in a patient centric manner through robust industrial scale systems.

The outcome is headlined by the provision of human centred connected technologies that shall shift the current model from reactive to proactive health-care management by enabling countless interwoven solutions seamlessly. Such a transformational shift changes behaviours towards self-empowered health and ignites a new breed of patient centric

products and services that will save lives and reduce the ever increasing burden on traditional health-care systems that are continually challenged with an aging population. Emerging data centric ehealth approaches harness holistic data management for ehealth to extend across technologies such as A.I., Machine Learning, Wearables, Telemedicine, Genomic and IoT interfaces - to name a few - means that in decades from now Government and Industry can be equipped to better address and even hope to eradicate or increasingly prevent diseases such as diabetes, heart disease and cancer plus provide more personalised direct care and diagnoses through more efficient and effective forms – including in home care – by positioning the individual to sit and act at the centre of their health requirements through data insights, innovative products and hyper personalised services.

During times of crisis as seen with the COVID-19 Pandemic ehealth data facilitation “utility” can service our Nation faster during a cycle whereas “unknowns” change overnight requiring the urgent need to deploy agile solutions at scale with sometimes only days to respond to the evolving requirements via point solutions that navigate technology interconnects plus systems supports which demand interoperability and go far beyond initial Contact Tracing apps or help make it truly effective.

During the Pandemic Countries have needed to become more agile in providing a range of COVID-19 solutions to assist front line workers, Allied Health, Hospitals, Researchers, Clinicians, GP’s, First Responders, and care givers whilst not forgetting our citizens, particularly those who are more vulnerable in our society such as seniors, regionally displaced, indigenous and individuals with disabilities or those who reside in full time care facilities.

Data facilitation platform technologies with embedded PET assist in placing Government Health Agencies at the epicentre with an enhanced ability to rapidly respond to ever increasing demands. New Patient Centric step change models are flexible for fast and agile implementation with the ability to interoperate across data hungry systems and cascade through end to end frameworks with API’s that bridge existing systems in a compliant manner. With Governance and seamless delivery “direct to patient” services can be routed with interconnecting B2B distribution through a multi-dimensional eco-system operating on agnostic data rails and internet connectivity. Not to mention federated A.I. and Machine Learning aspects.

Utilising PET to onboard a game changing moment in eHealth.

Today’s mobile population navigates a complex health landscape, crossing between specialties, organisations, sectors, regions or even countries. However, while the individual traverses the health ecosystem their data tends not to follow them. Our health also extends well beyond traditional healthcare settings and includes our lifestyle and behaviours whether at home, work and at play. Much of our habits and behaviour are locked up in data which surrounds our lives. World events such as COVID-19 create an unprecedented challenge for governments when it comes to surveillance and tracking while creating an

imperative to help individuals manage their life. Patient centricity is the philosophy of equipping individuals with data and technology enabling them to better manage their lives while respecting their privacy and rights.

WDX consumer centric solutions which feature PETs represent new approaches to enable the rapid adoption of digital health services to support the COVID-19 effort with two key aims:

- Equip individuals with a data wallet to gather up data across their life.
- Provide a COVID-19 related set of apps and services.

This approach enables industry to collaborate globally to bring together a unique set of competencies and capabilities to help address the crisis and evolve Health-care ecosystems beyond COVID-19.

When trust is restored via PETs that offer citizens a personal data platform which provides individuals with the ability to own and control their data which promotes trusted handling of personal or sensitive data. To engender trust, we engage with award-winning market leading compliance framework with platforms for jurisdictional accreditation and distribution of health apps, enabling the safe and sustainable adoption of digital health apps and services at scale.

Rapidly deploying these technologies will provide a foundation of capabilities which can not only support the immediate COVID-19 response but additionally offer:

- Monitoring and self-assessment of individuals.
- Supporting self-management for at home care.
- Connecting people with health, wellbeing, and condition specific digital services.
- Medical research now and in the future.

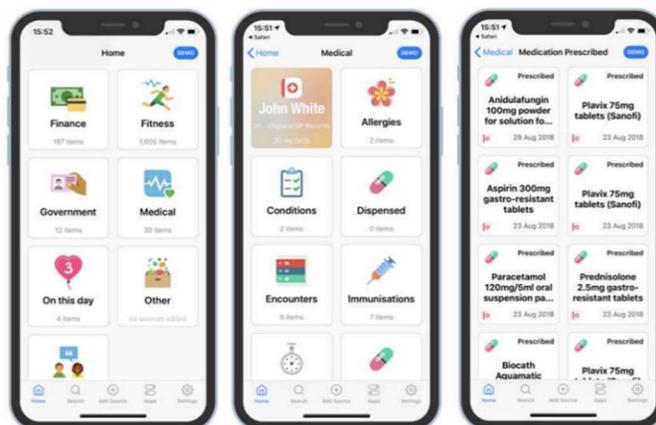


Figure 1 - digi.me personal data library platform

The core aim for PET based capabilities is to underpin digital eHealth futures in terms of:

1. Enabling the accelerated the adoption of digital health through better access to data and a trusted complaint framework of services. Equipping individuals with the data and tools they need to better support themselves reducing the burden on the healthcare and providing a basis for wider national distribution.
2. Putting in place core set of capabilities and competencies that would allow a much more rapid and immediate technological and data driven response to future pandemics or emergency situations.

With existing privacy enhancing technology, such core capabilities can be deployed today to provide the foundation of an accelerated digital health adoption.

PETs can also be immediately applied into several other industry sectors such as Social, Finance, AdTech and other markets by supporting innovation leaders with the capability to address priority needs. In eHealth this might be applications for anxiety amid mental health, Asthma, Chronic obstructive pulmonary disease (COPD) Diabetes and other priority areas escalating within the public health system.

Overall, we remain convinced Privacy Enhancing Technologies and well-considered Privacy reforms will drive digital transformation and enhance the data economy by leveraging the Regtech sector to ensure consumer centric technologies are the cornerstone of citizen data rights.

As Privacy and Data Sharing platform leaders, we hope this submission is of assistance to OSPT, please feel free to contact us for any further clarification or continued input in relation to this submission.

We look forward to continued participation.

Kind regards,

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