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# **Tell Us ~~Once~~ Twenty?**

A review of initiatives that allow people to share their support needs with multiple organisations

**April 2026**

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# Foreword

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The authors of this report have all helped shape 'Tell Us Once' (TUO) systems.

We've all worked on initiatives that let people more easily share information about themselves with multiple organisations to get a better service, equal access, or extra help or understanding.

But, more importantly, we have also used TUO systems in our own lives. And we therefore not only know what such approaches can achieve, but the real difficulties in using them too.

## Unconnected

As it stands, the biggest single difficulty with TUO activity in the UK is that is **unconnected**.

Currently, we have islands of uncoordinated effort. Here, determined people are working hard to develop solutions that meet the specific data challenges their sectors are facing.

And within these sectors - from energy to education, banking to bereavement - progress is happening (and in this report, we identify 20 TUO initiatives making a difference).

But no-one is just an 'energy customer' or 'employee'. Or is only an 'NHS patient' or 'student'. Instead, we rely on multiple services in different sectors to keep our whole lives working.

This means we need to put 'people' at the centre of our TUO efforts (rather than 'sectors') and enable everyone to share and control their personal information in a way that works for them.

## Re-connected

To achieve this, we can no longer work in isolation. As a first step, we need to build bridges between our TUO 'islands', so if people tell one sector about their support needs, they are then given the choice and help to share that information with another essential service sector.

As a second step, we also need to agree a common language across our sectors to describe the support needs or adjustments that people require. Only this will let the data we choose to share about ourselves be easily 'ported' and acted-upon by whichever organisation receives it.

And to achieve all this, we need our 'islanders' to be ready to collaborate, and perhaps even concede a little ground, so we can advance as a collective.

We therefore offer this report as a small step towards such an outcome and invite others to join us to connect, align, and amplify our individual efforts into a collective change.

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**Key information:** author biographies are in Appendix 1. Definitions of central terms are in Appendix 2. These include a recognition that for some people, concepts like 'disclosure' are not always neutral descriptions of a process where people tell organisations something about themselves. Instead, they can also invoke negative associations of guilt, societal judgement, and a lack of control over not only what is 'disclosed', but also the actions following this. Similarly, 'disabled person' and 'vulnerable consumers' are used in this report for brevity and consistency, but we acknowledge other terms exist including 'consumers in vulnerable situations' or 'people who require extra help'.

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This paper can be downloaded at:

[www.moneyadvicetrust.org/vulnerability](http://www.moneyadvicetrust.org/vulnerability) | [www.WhatWeNeed.support](http://www.WhatWeNeed.support)

# Executive summary

## Tell Us Once

This paper is about vulnerability<sup>A</sup>, disability, and data-sharing across a range of different sectors. It focuses on **'Tell Us Once'** (TUO) approaches that allow people:

- to share information about a situation or support needs with **multiple organisations**<sup>B</sup>
- using a **single process** or **resource** (rather than engaging with each organisation in turn)
- with the primary aim of ensuring these organisations **act on** the shared information.

TUO systems aim to let people in their roles as a consumer, patient, or carer/third-party to 'share and be supported'. However, while a familiar concept, TUO approaches in the UK have never been mapped. We undertook a review between June-December 2025 to address this.

## Told You Twice

This is our **second paper** about vulnerability, disability, and data-sharing schemes.

Our first paper outlined 10 guiding principles to help design better data-sharing schemes<sup>1</sup>. These principles were created by a group of authors with technical and lived experience.

This paper builds on this earlier work. Its objectives are to:

- map and describe **TUO initiatives** in active use in the UK
- include approaches using **digital, physical, or hybrid** approaches to sharing
- reflect on how these initiatives compare to selected 'good design' principles.

## Tell us Twenty

This review's main finding is that there are at least **20 TUO initiatives** in operation in the UK. These span sectors from energy to education, and circumstances from death to direct debits.

Our **key reflection** is that it is not possible for disabled or vulnerable people to truly 'TUO'. This is because a fragmented and unconnected landscape of TUO initiatives exist.

<sup>A</sup>This paper uses 'disabled person' and 'vulnerable person' for brevity and consistency. However, other definitions exist (see Appendix 2), including 'people in vulnerable situations' and 'people who require extra help'.

<sup>B</sup>Some TUO approaches involve people being able to share information about themselves in a single organisation just once and having this recorded, shared across different units in that organisation, and acted-on in future actions/interactions.

However, our **conclusion** is creating one single TUO system is too ambitious at the current time. Instead, we should focus on improved sharing - controlled by users - between existing schemes.

To do this, we need to understand each TUO approach in operation and the data they share. The profiles of the TUO initiatives in this paper aim to help us to do this.

## The Twenty

Each of the 20 approaches we identified were put into a category based on stated/perceived purpose<sup>c</sup>.

### Common essential services (n=4)

- **Notice of Correction:** a 200-word credit report note explaining personal circumstances to lenders.
- **Priority Service Registers:** utility databases that record and prioritise customers with extra needs.
- **Support Hub:** online platform to share communication and support needs with banks and utilities.
- **Vulnerability Registration Service:** online service to notify needs to subscribing organisations.

### Death and bereavement (n=5)

- **Death Notification Service:** digital service to notify financial organisations about a person's death.
- **Life Ledger:** digital service to notify companies in multiple sectors, featuring a pre-death 'info vault'.
- **Notify Now:** referral-only professional platform for notifying organisations about a death.
- **Settld:** bereavement notification service which also captures the notifier's own support needs.
- **Government Tell us Once:** reporting service to multiple govt. departments and local agencies.

### Health and social care (n=4)

- **About Me:** NHS standard for patients to share personalised "what matters to me" text with services.
- **Accessible Information Standard:** NHS standard for recording and sharing support needs.
- **This is Me:** written tool for sharing dementia patients' preferences and routines with care givers.
- **Universal Care Plan for London:** digital tool to share care preferences with clinicians.

### **Retail, leisure, or transport (n=5)**

- **Hidden Disabilities Sunflower:** lanyards and cards to signal non-visible disabilities or support needs.
- **JAM Card:** a card and app allowing those with communication barriers to request "Just A Minute".
- **Access Card:** disability card communicating adjustments to leisure and venue operators.
- **Passenger Assistance:** app for rail passengers to book assistance and share needs with operators.
- **WelcoMe:** platform for sharing support needs and tips with participating venues in advance of visit.

### **Work or higher education (n=2)**

- **AXS Passport:** online platform for sharing reasonable adjustments for work or education contexts.
- **Health Adjustment passport:** paper-based Government form for describing reasonable adjustments.

### **What is happening?**

Within each of the five sectors, initiatives had different strengths and areas for improvement.

#### **1. There are four established but largely unconnected essential service sector TUO initiatives.**

Three **do not** give users a choice over who their data are shared with, nor information about who may have viewed or received their data.

None of the approaches are linked or share data with one another, all use different support need definitions, and users cannot 'share once' across the systems.

Financial services and utility companies participate in these, but telecoms and delivery firms do not appear to (an omission given their centrality to the lives of many disabled people).

<sup>c</sup> Where a TU approach could have been put in more than one of the above categories this is noted in the main text.

<sup>d</sup> An essential service is something that consumers cannot do without to live their everyday lives. These potentially include financial, energy and water, phone and internet, postal and delivery services.

**2. Five death notification TUOs exist - ranging in accessibility and support for the bereaved.**

The most accessible offers digital, telephone, video, and face-to-face registration, one other provides digital or phone notification, and the other three are all digital-only.

Only one TOU initiative asks the bereaved user if they have support needs themselves.

**3. Among the four health/social care approaches, the first physical TUO was encountered.**

This was a booklet setting out personal history, care preferences, and communication needs.

The others focused on digital, including the use of NHS standards for defining support needs. However, just one of these gave the option (via the NHS app) for users to view their support needs, while the others required a professional to update or make changes to their record.

**4. The retail, leisure, and transport sectors used hybrid physical and digital TUO approaches.**

All five TUO initiatives focused on improving the accessibility of in-person interactions, with three TUO approaches combining physical cards or lanyards with digital apps and websites.

Designed for in-person situations, the initiatives only partially covered interactions via telephone, written communication, or other channels (or not at all).

**5. In the workplace and higher education sector, two flexible 'passport' tools were identified.**

One digital and one paper-based passport let users share profiles describing their required reasonable adjustments with multiple organisations.

The digital option used an AI chatbot to suggest adjustments users may not have considered.

Both passports, however, relied on organisations being able to receive and integrate the information (which was sent or emailed) into their systems.

Critically, none of the above approaches used the same support code definitions or language to describe needs or adjustments. Equally, to users' potential detriment, none of the initiatives appeared to acknowledge, signpost to, or collaborate with any other TUO system.

## What needs to happen?

We currently have a **TUO archipelago** - scattered islands of divergent and unaware data activity. Designed to meet the needs of specific sectors, each works on its own TUO problem in isolation. This has resulted in an array of distinct models from which things can be learnt.

But in remaining unconnected from their neighbours, and without either bridges or a common language to share information, the larger consumer problem remains unresolved: the need for people to repeatedly notify, inform, or disclose<sup>E</sup> to the key organisations in their lives.

### **‘One ring to rule them all’: not an option**

We do not, however, believe that a single TUO system - covering all major sectors - is feasible.

Neither Government interest, commercial appetite, or public trust currently exists for this. Instead, we need to allow data to more easily move between those TUO initiatives that do exist.

One way is through collaboration between the different ‘islands’ of TUO approaches on data-sharing agreements, standard definitions of common support needs (for data portability), and - critically - user control over who sees their data.

However, if TUO providers prefer isolation over collaboration, the Data (Use and Access) Act 2025 offers another way: the right for people to instruct a company to send the data it holds about them to another company.

Such ‘data portability’ allows for **user created and controlled data-sharing** across services aided by digital wallets and identities. This could offer new ways for TUO objectives to be achieved.

<sup>E</sup> This paper uses the terms ‘disclose’, ‘notify’, and ‘inform’ to describe the process of a person telling an organisation or TUO initiative about a situation, support need, or something else about themselves. While some readers may prefer one term to be used over another, or associate a particular term with negative connotations, all three are commonly used across the different sectors and are therefore employed in this review.

## Who needs to take action?

### A. The ICO must consider TUO approaches in their 'guidance for organisations' resources.

Despite its growth in the UK, there is only one passing reference to TUO in the ICO guidance<sup>2</sup>.

Given the centrality of personal and special category data in the design of any TUO approach, this absence of recognition or guidance from the ICO does not align with their stated strategic ambition to "safeguard and empower the public, particularly vulnerable groups"<sup>3</sup>.

While an ICO data-sharing code exists<sup>4</sup>, this considers broad 'business to business' scenarios, and does not consider TUO schemes that have the specific purpose of sharing peoples' data.

Critically, given that control and transparency have been repeatedly shown as the preferred 'default setting' of disabled people or those in vulnerable circumstances, a large gap exists between what many TUO approaches currently offer, and what users want.

### B. The time is now for energy, water, and financial TUO systems to sign-post to one another.

Again, we are not calling for a new initiative, unified database, or direct data-sharing flow. Instead, as a simple step, we would like people completing a TUO journey with an energy or water firm to just be sign-posted to a TUO journey for financial services (and vice versa).

Doing this would represent the **building of a small bridge** between the 'isolated islands' of TUO activity in these sectors, and a step that could practically help millions of people.

And in this vein, we would equally encourage telecoms and delivery services to engage with the TUO agenda, given the importance of these services in the lives of many disabled people.

### C. The Smart Data Council (chaired by Liz Lloyd, Minister for Digital Economy) should help create the conditions for standardised definitions of the most common support needs.

The portability of a person's data is key to the Government's digital and economic growth targets<sup>5-6</sup>. Aiming to allow users to more easily obtain, collate, and use the information held about them by firms, this is likely to be a key driver for activity in the next decade.

While disabled people or those in vulnerable situations may not ask an organisation to send them data held about their support needs (as they already know this), they could however ask for it to be shared with another organisation or stored in a third-party wallet/identity.

And it is here, that a lack of standardised definitions of the most common support needs could hinder sharing. Given the range of definitions found in this review, organisations receiving such data may find it difficult to integrate this into their systems or workflows.

Standardised definitions of the most common support needs would help prevent this issue while making it easier for people to understand what different TUO systems offer.

#### **Further information: review methodology**

The research team:

- searched the published literature (including the web)
- asked experts and specialists for examples of TUO initiatives
- registered/used each eligible initiative (demonstrations arranged if this was not possible)

The team described each initiative in terms of:

- **purpose** (who is it for? | what does it do?)
- **use** (how does it work? | what is shared and with whom?)
- **control** (what choices over data-sharing does the user have?)
- **design** (how simple is it? | how accessible is it?)

These categories reflected key elements of our '10 principles for designing vulnerable consumer data-sharing programmes' guide from 2024<sup>1</sup>, and the 15 principles of the 'Data for People' report published by the Think Local Act Personal<sup>7</sup>. The team then contacted each TUO initiative to share this description for respondent validation, accuracy, and feedback.

# A. What is ‘Tell Us Once’?

## In this paper

The term ‘Tell Us Once’ is a familiar one. But it can be used in different ways.

In this paper, we map and describe TUO schemes that allow disabled people or those in vulnerable situations to share information about a situation or support needs with **multiple organisations** via a single process, platform, tool, or resource.

This includes digital platforms or websites, and non-digital schemes using physical cards or media.

But whatever its form, the same aim remains: to ensure that the information shared is **then practically used** to support the person from that point onwards.

## In real life

Real life, however, isn’t lived on paper.

In this review, we therefore also share people’s real experiences and data about TUO - good and bad - plus research findings from the peer-reviewed and grey literature.

Throughout, what will become clear from these insights is the significant role that TUO approaches could play in changing people’s lives that goes beyond the mere ‘saving of time’. Here TUO approaches have been identified as having the potential to bring about significant:

- **change** - information is shared by TUO initiatives with the aim of improving the access, use, or benefit a person gets from a product or service
- **inclusion** - TUO initiatives can help people to tell more organisations about their situation or support needs (overcoming barriers to disclosure or exclusion from a service)
- **control** - TUO approaches can give people transparency and control over who their data are shared with, for what purpose, and for how long (building trust in the process)
- **possibility** - it isn’t just the ‘time saved’ by using a TUO approach which is key to people but the increased choices, controls, and meaningful use to which that time can be put.

## Now and later

All regulatory bodies want organisations to deliver good person outcomes and experiences. And as we shall see (Section B), they have identified TUO as one way of achieving this now.

However, alongside this current regulatory target, recent changes in technology and law - like the Data (Use and Access) Act 2025 - have opened-up new possibilities for future TUO approaches.

But before we can take such opportunities, we need to fill a long-standing gap in our knowledge: which TUO approaches are already running in the UK? And what can we learn from them?

# Figure 1: definitions and dimensions

## **Tell Us Once - within a single organisation**

For some people, TUO involves individuals being able to share information about themselves with a **single organisation just once** and having this recorded and acted-upon thereafter.

In principle, this form of TUO stops people having to repeatedly share the same information each time they contact the same organisation.

An example would be a person telling an energy firm about a support need. After recording it, the firm meets the need in future interactions, without further person prompting.

## **Tell Us Once - across multiple organisations**

For other people, TUO is where individuals can share information about themselves with **multiple organisations** through a single process and have this acted-upon thereafter.

Where a person wants to share information with more than one organisation, this TUO approach removes the need for people to contact or engage each organisation in turn.

A digital example would be a person using a TUO website to let multiple organisations know about the death of a family member, rather than having to contact each organisation in turn.

A non-digital example could be a physical card listing a disabled person's accessibility needs which allows them to secure reasonable adjustments at entertainment venues.

### **Tell Us Once - relationship to other person data-sharing designs**

Tell Us Once is one form of data-sharing scheme. But other approaches exist (and can overlap):

- **data pooling** - these rely on a person disclosing information, but once this has happened organisations participating in the sharing network or 'pool' can access and view that shared data (as well as potentially adding information to the pool). There may (or may not) be eligibility criteria that firms need to meet to be access these data.
- **dynamic data-analysis models** - these may be used in planning or responding to events, interruptions, or emergencies. Used to facilitate resource allocation or triage, they can involve firms collating a range of non-vulnerability data sources into their analyses (such as flood warnings or other event information), alongside vulnerability data.
- **'open' or 'smart' data** - these allow third-party service providers to access data held by another organisation with the person's permission (e.g. 'Open Banking' where transaction data is accessed to provide a person with a financial service).

## B. Short history of Tell Us Once

There is no published history of ‘Tell Us Once’ services in the UK.

However, five strands can be pieced together to trace its development over time.

### 1. Lived experience

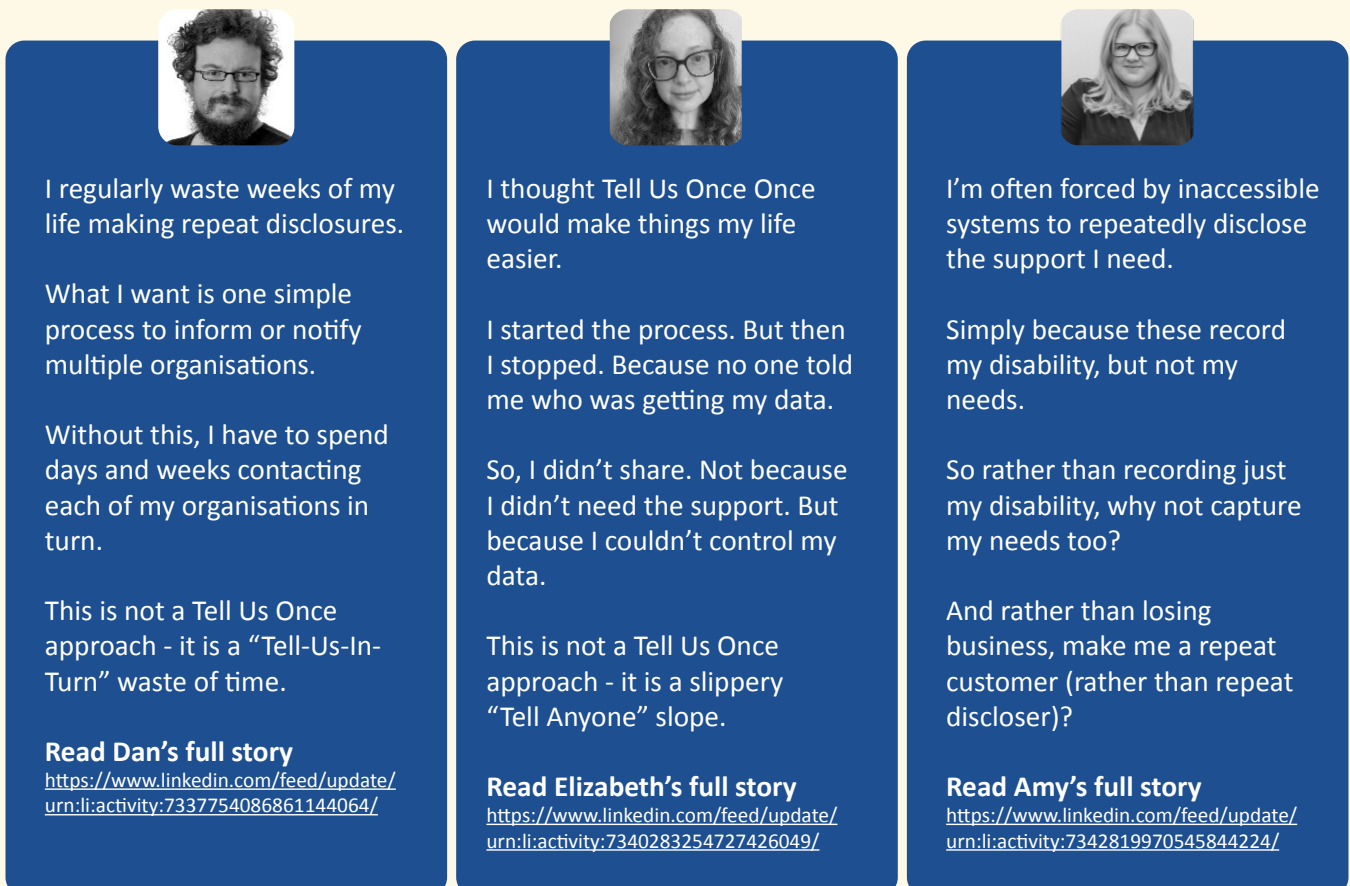
For decades, disabled people and individuals in vulnerable circumstances have shared their experience of having to repeat their situation, health, or support needs to key organisations.

This may involve repeated notifications to a single bank or essential service firm<sup>8</sup>, the ‘one-by-one’ calling of multiple companies to share the same information<sup>9</sup>, or recurrent contact or assessment across the Government welfare benefit system<sup>10</sup>.

The case for TUO initiatives to address such problems is therefore neither recent nor novel. But so too, is the accompanying caveat that without safeguards or controls any centralised source of information could be used in harmful or discriminatory ways<sup>11-12</sup>.

This concern needs to be taken as seriously as any enthusiasm or case for TUO or data-sharing. Consequently, as Figure 2 illustrates, the themes of choice, control, and transparency have become central to lived experience debate about the design of TUO initiatives in the UK.

**Figure 2 - Tell Us Once: Dan, Elizabeth, and Amy’s lived experience**



In addition, some people have also noted that terms like ‘disclosure’ are not always neutral descriptions of a process where people tell organisations something about themselves<sup>13</sup>.

Instead, they can also invoke negative associations of personal guilt, societal judgement, and a lack of control over not only what is ‘disclosed’, but also the actions that follow from this.

## 2. Government intervention

It is arguable<sup>F</sup> that the first TUO approaches in the UK can be traced back to Government action.

One early example may lie in the **1974 Consumer Credit Act**. This let people place a ‘Notice of Correction’ (NOC) on their Credit Reference Agency file to explain any circumstances (such as illness) that related to a recorded debt or missed payment. Aiming to provide potential creditors with relevant context, over time people also began to use NOCs to give creditors instructions (e.g. ‘Do Not Lend’ notices placed by people concerned about their gambling).

An alternative candidate for the first TUO approach in the UK came 37 years later after the NOC, through the Government’s Tell Us Once Death service. Launched in 2011, this gave people in England, Scotland, and Wales a single process through which to notify multiple Government departments and agencies about a person’s death.

And, in May 2024, the Sunak Conservative Government announced work on a new TUO system: the **Share Once Support Register**<sup>14</sup>. Aiming to “ensure extra help is available to people when they need it”, this initiative wanted to enable people to share their situation and support needs through a single process across the energy, water, and telecommunications sector. However, following the new Starmer Labour Government coming into power in July 2024, work on the SOS Register appears to have significantly stalled (and perhaps even ended).

## 3. Firms and regulators

In the **energy and water sector**, many firms have been recording data from disabled or vulnerable customers about their support, safety, and communication needs since the 1990s.

This data has been stored across multiple organisational databases (with each database being owned by individual firms or distributors). And while there are around 45 PSR databases in operation today, these are typically known by the singular title of the ‘Priority Service Register’.

Despite this early data recording within individual firms, the sharing of PSR data between the majority of energy and water firms arguably only began at scale in April 2023. Prior to this, the ongoing Northumbrian Water-led ‘Support For All’ initiative has made valuable progress with a smaller number of organisations (including telecoms firms and charitable support groups)<sup>G</sup>.

<sup>F</sup> We partly make this argument to encourage others to identify and propose alternative examples of early TUO approaches.

<sup>G</sup> As it does not yet have a consumer-facing mechanism (online, telephone, or other channels) through which the disclosure of circumstance or support data can be made, ‘Support For All’ has not been included in this review.

In the **financial services sector**, some TUO approaches have let customers notify multiple firms about a situation. Here, the Death Notification Service (launched in 2018) may have the largest 'reach' across financial services for reporting customer deaths. Meanwhile, from 2023 onwards, Support Hub has let people share support needs with 32 financial and energy brands.

Outside of the energy, water, and financial service sectors, TUO activity has been more muted. This may reflect the emphasis that regulators like Ofgem, Ofwat, or the FCA have put on 'TUO'.

However, it has meant that, for example, the potential for **telecoms firms** to link-up and share data from their 'priority fault repair' lists (offered to disabled customers, incapacitated and housebound individuals, and households with severely ill children) has not been fully realised.

Equally, it has also meant that sectors such as **Local Authorities** or **housing** have not been as involved in TUO initiatives as they could have been, although some TUO approaches like the Vulnerability Registration Service (launched in 2016) have engaged with these sectors.

#### 4. Technology

Any history of TUO is also a history of technology.

Our ability to share personal information has become easier due to technological advance. Most notably, our increasingly digitally connected society has meant many of us have the tools in our pockets and homes with which to share data about ourselves.

However, the passing of the Data (Use and Access) Act 2025 will fuel the TUO debate further<sup>15</sup>. At its centre, this uses the concepts of 'data portability' and 'smart data' to give people a stronger legal right to ask a company to send the data it holds about them to another company.

This may not sound earth-shattering. But it could introduce two possibilities:

**First**, where a person (a) notifies one company (such as a bank) about their support needs, and (b) that company records information about this support need in its system, the Act then (c) provides a legal framework for the person to request this data is shared with a different essential service (such as a water company).

This opens-up the potential for 'user created and controlled' data sharing across different services to achieve what a person wants, rather than having to wait for such networks to be developed between firms and sectors.

**Second**, where companies (a) hold data about a person's support needs or service use in their system, people can (b) request this data is shared with a trusted-third party.

This opens-up the potential for data from multiple companies to be stored and managed in a digital wallet owned by the person, giving them an 'at a glance' overview of which companies are meeting which support needs. Further, this could help people share their needs or circumstances with new providers or update existing ones on changes. Finally, third-party applications might also combine a person's support need and service use data to find a different provider that would better meet a person's needs.

Clearly, this overview simplifies the technical and legal factors underpinning such developments. However, the potential impact on data-sharing that could flow from this situation is significant.

## 5. Research

While any history of TUO is technological, it is also human.

And there is no more human instinct than to consider whether using any new tool or technology could lead to potential harm, detriment, or negative outcomes.

Understanding this is critical, as such an evaluation could lead to individuals not informing TUO initiatives about their situation or needs, and missing out on action to better support them.

### What do we know?

Currently, much of what we know about the public perception of TUO initiatives comes from research undertaken with people with mental health problems.

Before 2024, this research often only collated the views of people with mental health problems, but later work has compared the perceptions of those with or without mental health problems.

This **earlier collection** of studies found that among people with mental health problems:

- **low disclosure:** only 11-14% of participants report having ever told an essential service about their situation, support needs, or reasonable adjustments<sup>16</sup>
- **cited barriers:** the belief that disclosure wouldn't lead to action, could lead to worsened service delivery, or might be used against them, were all reasons for non-engagement<sup>17</sup>
- **still open:** despite such difficulties, 47-73% of participants still said they would be open to notifying a range of essential services about their situation in the future<sup>18</sup>
- **future design:** people identified data security, regulator scrutiny, user control over who data were shared with, and a focus on their support needs (rather than condition) as being key to their decision to use (or not use) any 'vulnerability data-sharing service'<sup>19</sup>.

**Later research**, again conducted by Money and Mental Health (MMH) found that:

- **use:** 53% of people with mental health problems, and 46% of people without, report they would be likely to use a TUO initiative to share any support needs with multiple services
- **control:** 81% of people with recent mental health problems, however, are concerned about having no control over what specific information is shared
- **fear:** 76% of people with recent mental health problems reported being worried that shared data could be used in negative ways (e.g. to limit access to future services)
- **trust:** 69% of all participants said that if something went wrong with a support-need sharing system, they would lose general trust in all digital systems.

**Finally**, similar concerns were found in research by Which?. In their study of over 2000 disabled participants, 63% said they would use TUO systems to share support needs, but only if they could select the companies their data were shared with<sup>20</sup>.

Taken together, the current research literature indicates that we should not develop TUO initiatives that repeat avoidable barriers, use opaque or off-putting language, or simply 'go against the grain' of what people say they want from TUO.

### FIGURE 3: LEARN FROM WHAT WE ALREADY KNOW

Historically, disclosure levels to key organisations have been low.

Sector	% of respondents who report ever disclosing mental health condition or support needs to a firm (by sector)
Water	11%
Energy	12%
Telecoms	13%
Financial services	14%

Notes: these data also reflect earlier findings from MMH in 2016 (5500 participants)<sup>21</sup>, Mind in 2011 (878 participants)<sup>22</sup>, and Mind in 2008 (1804 participants)<sup>23</sup>, where consistently only a minority of respondents reported disclosing to selected essential service sectors.

### **Multiple reasons for such low levels of disclosure have been repeatedly documented.**

Quantitative surveys from MMH and Mind have repeatedly outlined these barriers. These are listed in broad 'higher to lower' frequency order across the studies conducted:

- disclosure would make no difference
- dislike of sharing details of condition
- fear of not being treated sensitively
- concern about how disclosed information would be used
- worry about access to future services
- thought they would not be believed or would be treated unfairly
- embarrassed to share
- concerned about impact on benefits.

Notes: among the qualitative reasons given **for making a disclosure**, securing **practical change and support** was key, as well as having control over what disclosed data were recorded, used and shared<sup>24</sup>.

### **But disclosure levels - if these lessons are learnt - do not have to remain this way in the future.**

A sense of positive potential may be beginning to emerge among some people. Recent small-scale research from MMH (2023 with 178 participants) found<sup>25</sup>:

- 47-73% would consider disclosure to an individual essential service in the future
- the top priorities to people in the design of a data-sharing system were:
  - knowing how their information would be stored and protected (28%)
  - strong regulation of how any information was collected and shared (18%)
  - focus on the disclosure of needs rather than condition (12%)
  - controlling which organisations information was/was not shared with (12%).

## C. The Review: what did we do?

Although a familiar concept, TUO approaches in the UK have never been mapped or described. We therefore undertook a mapping review which ran from June to December 2025.

### Objectives

1. **identify** eligible TUO initiatives operating in the UK
2. **describe** these initiatives (using comparable headers and criteria)
3. **recommend** improvements in practice.

### Eligibility

The review included TUO initiatives that:

- allowed people to share information about themselves **with multiple organisations**
- shared data **digitally** (e.g. web platform) or **non-digitally** (e.g. a physical ‘about me’ card)
- operated in **any sector** in the UK (including private, public, or third/voluntary).

The review excluded TUO initiatives that:

- allowed people to share information solely within a **single organisation** (e.g. between different departments, or with different brands across the same commercial company)<sup>H</sup>

### Method

To **identify** initiatives, we undertook:

- a literature review (peer-reviewed and grey) using the search term “Tell Us Once”
- an online review using the same search term
- key informant engagement to receive recommendations for potential TUO initiatives.

**Once identified**, we:

- registered/tested the product as a user
- or obtained a demonstration from the provider
- compiling a description of each TUO initiative using standardised headings (Figure 4).

For **analysis and write-up**:

- all data were then placed into a database, analysed thematically, and written into profiles
- each TUO provider was sent their profile for comment (to ensure accuracy and balance)
- and this report was then compiled and finalised.

<sup>H</sup>This exclusion was due to it being unfeasible to identify and review such TUO systems due to both their potential number across the UK, and also their visibility to external reviewers. We took the decision, however, to include any TUO initiatives that shared person information across different Government Departments or the NHS/Social Care system.

## Figure 4: review checklist

### **Purpose**

Who is it for?  
What does it do?  
What doesn't it do?

### **Use**

How does it work?  
What information can be shared?  
Which organisations can it be shared with?

### **Control**

Can the user see and control what is shared?  
Can the user see and control which organisations it is shared with?  
Can the user change, update, or delete their information?

### **Design**

How simple is it to share?  
How accessible is it share?  
Who might be excluded?

### **Summary observations**

What are its strengths?  
What are its areas for consideration?  
Is there scope for collaboration?

## D. The Review: what did we find?

### Overview

We identified 20 TUO initiatives related to disability or vulnerability (Figure 5). These were grouped into five categories:

1. **common essential services** - sharing data with financial, energy, or water firms (n=4)
2. **death and bereavement** - informing multiple organisations about a person's death (n=5)
3. **health and social care** - alerting NHS and social care to key information (n=4)
4. **retail, leisure, or transport** - ensuring organisations are aware of support needs (n=5)
5. **work or higher education** - preparing employers or providers to meet need (n=2)

Categorisation was based on each initiative's perceived primary purpose or sector-reach.

### Major findings

- Within the **common essential services**, we found that three out of four TUO approaches did not give people a choice over who their data were shared with, nor information about who may have viewed or received their data.
- Among **death and bereavement** TUO approaches, the need for control over data-sharing is arguably lesser. While three out of four initiatives reported extensive cross-sector coverage or individual sector reach, only one captured the bereaved person's own support needs.
- The **health and social care** sector were the first in our review to use a physical TUO tool to share personal support needs (n=1), although digital TUO approaches were still the norm, including NHS data standards and care planning apps.
- Within the **retail, leisure, and transport** sectors, three of the five TUO approaches used physical resources (such as cards and lanyards), which were sometimes supplemented by a digital app or website.
- In the **workplace and higher education** sector, two TUO 'passports' were identified (one digital, one document-based). Here users created profiles detailing their reasonable adjustments, which the user then shared with organisations via email/post/in-person.
- **Collaboration across sectors** - there was not a 'common language' across the TUO initiatives to describe support needs or reasonable adjustments. While different sectors will have some unique support needs, standard definitions of such needs would aid wider data-sharing.

### Data processing

This report did not undertake a detailed review of each TUO initiative's data processing policies. All reviewed initiatives reported that they fully met data protection legislation and had robust governance data policies and contracts in place. However, for readers interested in this detail, links to each TUO initiative's Privacy Notice are given at the end of each report section.

## Figure 5: identified TUO approaches

### Essential services (n=4)

- **Notice of Correction:** a 200-word credit report note explaining personal circumstances to lenders.
- **Priority Service Registers:** utility databases ensuring customers with extra needs are prioritised.
- **Support Hub:** online platform to share communication and support needs with banks and utilities.
- **Vulnerability Registration Service:** online service to notify needs to subscribing organisations.

### Death and bereavement (n=5)

- **Death Notification Service:** digital service to notify financial organisations about a person's death.
- **Life Ledger:** digital service to notify companies in multiple sectors, featuring a pre-death 'info vault'.
- **Notify Now:** referral-only professional platform for notifying organisations about a death.
- **Settld:** bereavement notification service which also captures the notifier's own support needs.
- **Government Tell us Once:** reporting service to multiple govt. departments and local agencies.

### Health and social care (n=4)

- **About Me:** NHS standard for patients to share personalised "what matters to me" text with services.
- **Accessible Information Standard:** NHS standard for recording and sharing support needs.
- **This is Me:** written tool for sharing dementia patients' preferences and routines with care givers.
- **Universal Care Plan for London:** digital tool to share care preferences with clinicians.

### **Retail, leisure, or transport (n=5)**

- **Hidden Disabilities Sunflower:** lanyards and cards to signal non-visible disabilities or support needs.
- **JAM Card:** a card and app allowing those with communication barriers to request "Just A Minute".
- **Nimbus Access Card:** disability card communicating adjustments to leisure and venue operators.
- **Passenger Assistance:** app for rail passengers to book assistance and share needs with operators.
- **WelcoMe:** platform for sharing support needs and tips with participating venues in advance of visit.

### **Work or higher education (n=2)**

- **AXS Passport:** online platform for sharing reasonable adjustments for work or education contexts.
- **Health Adjustment passport:** paper-based Government form for describing reasonable adjustments.

# **1. Common services**

(financial, energy, water, telecoms)

# 1. Common services (financial, energy, water, telecoms)

## 1. Common services: overview

The review identified four TUO initiatives related to common essential services:

- **Notice of Correction (NOC)** - this allows someone to add a short note to their credit file. In up to 200 words, this can explain circumstances (such as illness) relating to a recorded debt on or missed payment. Some people also give creditors instructions on how to treat them (e.g. 'Do Not Lend' notices from individuals with gambling-related issues).

Strengths: NOCs should be visible to any organisation eligible to access a credit file

Considerations: people cannot control who sees their NOC (which could be a concern, for example, if there are sensitive instructions re: health/addiction). They also must register NOCs with each Credit Reference Agency (CRA), as NOCs are not shared across CRAs.

- **Priority Service Registers (PSRs)** - run by energy and water sector companies, these are databases of customers in circumstances/with needs who potentially need extra support (including during supply interruptions). Registering themselves (or others in household), customers select from around 30 'needs codes'. Set-up by individual firms to support their customers, since April 2023, energy firms have shared data with water companies.

Strengths: data-sharing between PSRs should mean that people's needs are known by multiple essential services, rather than requiring customer notification with each service

Considerations: PSRs are still 'marketed' more as a way to inform one company rather than as a TUO for multiple firms. Users do not control who data are shared with - if more organisations (particularly non-energy/water) are shared with, this may deter disclosure.

- **Support Hub (SH)** - run by Experian, users can select their support needs (from a list of 52) and pick the financial service or energy brand to share with (from a list of 32). Written, phone, in-person, and 'life event-related' support needs form the core data-set.

Strengths: people select which organisation their data are shared with (and if people change or delete information, participating firms also do this). Support Hub data are not shared with the wider Experian CRA (or accessible to organisations as part of this)

Considerations: while including large UK brands, 31 of the 32 are financial service firms.

- **Vulnerability Registration Service (VRS)** - notifying themselves or a third party (Power of Attorney/Court of Protection Order evidence required), users pick their circumstances (from a list of 39) and are given related support needs to choose from (from a list of 141).

Strengths: the VRS aims to cover multiple service sectors, has a large list of support needs, and will deploy a 'Vulnerability Passport' function later in 2026<sup>26</sup>.

Considerations: VRS requires users' permission to share data with organisations. Users cannot, however, control or view the organisations data are shared with. VRS data are shared with intermediaries -such as TransUnion (UK CRA) - who can share VRS data with their own clients if a prospective, existing, or historical relationship exists with the user.

The screenshot shows the Experian website interface. At the top, the Experian logo is on the left, and 'Contact' and 'FAQ & Help' are on the right. Below the logo, there are navigation links: 'My Experian', 'Credit Cards', 'Loans', 'Car Finance', and 'Mortgages'. A 'Log in' link is also present. The main heading is 'Adding a Notice of Correction (NOC) for gambling'. Below this, there is explanatory text about the consequences of gambling and how to add an NOC. A section titled 'Add your details' contains a form with the following fields: 'Your name', 'Your reference number', 'Your email address', and 'Date of birth' (split into 'Day (dd)', 'Month (mm)', and 'Year (yyyy)' fields).

The screenshot shows the Priority Services Register (PSR) website. At the top, there is a weather warning banner: 'Met Office Yellow Warning Rain Yellow weather warnings are in force in places. There's a slight chance of localised power cuts. What should I do'. Below this is the PSR logo and navigation links: 'Home', 'Join the PSR', 'About the PSR', 'Am I eligible?', and 'The benefits'. The main heading is 'The Priority Services Register (PSR) is a free UK wide service which provides extra advice and support, including when there's an interruption to your electricity, gas or water supply.' Below this is a form to 'Enter your postcode below to find your electricity and/or gas distributor' with a 'Postcode' input field and a 'Submit' button. At the bottom, there is a section titled 'We've made it easy to join the PSR' with a short paragraph and an image of two elderly women.

### **1a. What is their purpose?**

Originally designed for one purpose, NOCs are now used by some people to provide direction to multiple creditors on how to better support them. Similarly, the PSR has evolved to offer a form of TUO approach for energy and water firm customers. SH and the VRS have a common purpose but give users different levels of control over which organisations data are shared with.

### **1b. How can they be used?**

While we only reviewed the online self-serve elements, all NOC schemes and PSRs appear to allow postal registration. Most PSR programmes also seem to offer telephone registration, and some PSR offerings provide registration journeys via SignVideo, email, and social media. SH and VRS have an online 'help' service (portal and email), but other channels are not offered.

### **1c. What is the degree of user control?**

SH was the only initiative that let users control which organisations data are shared with.

Less consumer concern over control may exist for NOCs (although an organisation viewing a credit record might see this, including not only creditors but other types of organisation too). And while current PSR data-sharing remains between energy and water firms, it is not clear that consumers would accept an absence of control if more organisations were added in the future.

VRS users cannot choose which organisations data are shared with. Information is also not provided on the VRS portal about which organisations have accessed a person's data (although users can write to the VRS for a record of this). The VRS can share user data with organisations that do not have an existing relationship with the user (for purposes such as credit application assessments), and also with intermediaries (including TransUnion and IE Hub). Intermediaries can share a user's VRS data with their own clients but only where a prospective, existing, or historical relationship exists with that user.

### **1d. How are they designed?**

NOCs are not a single system - users must either complete a different online form or write separately to each of the main CRAs (Experian, Equifax, TransUnion). Any subsequent change to a NOC on one CRA is currently not automatically copied to the other CRAS.

Multiple PSRs exist, each with their own design. However, 'thePSR.co.uk' acts as a partially single point of reference to direct people to their company's own PSR portals.

The VRS Privacy Notice section is well set-out. It does not explain if firms searching its database can record data 'back onto' their own database, or if any user updating information on the VRS portal can expect 'mirror changes' to be made on the databases of organisations who previously received VRS data about them. However, the VRS report that organisations receiving data are expected to routinely update this information at key points.

SH report that data are kept separate, not shared with, or accessible from, the Experian CRA. Consequently, organisations using the CRA cannot view SH data.

The screenshot shows the homepage of the Support Hub. At the top, there is a navigation menu with links: "How Support Hub works", "Who we work with", "About us", "Support by Condition", and "News & Resources". The main heading reads "Get the support you need. From the UK's leading organisations." Below this, a sub-heading states: "Support Hub is a free service where you can share your support needs with all your service providers in one simple process." There are two buttons: "Get started now" and "Learn more". Three icons with text describe the service: "You save time as you don't need to contact organisations separately.", "Helps you get better service and support from your service providers.", and "You control what information is shared. And with which organisations." The section "Connecting you with the UK's leading brands" features a grid of logos for LLOYDS BANK, HSBC UK, nationwide, Monzo Bank Limited, HALIFAX, The co-operative bank, TESCO Bank, and aqua.

The screenshot shows the homepage of the Vulnerability Registration Service (VRS). The top left features the logo "Vulnerability Registration Service" with three colored circles. The top right navigation menu includes: "Home", "About", "For Individuals", "For Businesses", "Our Partners", "Contact", and "Conference 2026". The main visual is a close-up of hands holding a yellow flower. The headline reads "Register Once. Be Understood Everywhere." Below it, a sub-heading says: "The Vulnerability Registration Service (VRS) helps you avoid repeating your circumstances by securely sharing your challenges and support needs with trusted organisations." A prominent blue button says "Register Here". At the bottom, a light blue banner contains the text "How VRS Works" and a button "Learn more about registering".

## 1e. Summary recommendations

All four approaches illustrate a different vision for TUO.

The NOC reflects the simplest vision with a free-text statement (in the person's own words) that any eligible organisation searching CRA credit files can access. However, a question remains: is this 'semi-open' system is right for sharing what could often be sensitive 'vulnerability data'?

The PSR - after a lengthy cycle of discussions - is now sharing data across energy and water firms. But while its lack of user control is arguably uncontroversial where data are shared just between these two sectors, will this hold if other types of organisation are added/shared with?

SH has been built around the principle of user control - with the ability for users to select which firms or brands they wish to share with (and which they do not). That said, 31 of the 32 brands are financial service companies - could it therefore expand further across sectors?

The VRS is a non-profit initiative that aims to share data across multiple sectors. It also lets users register 3<sup>rd</sup> parties. Does, however, the current lack of user control over which organisations their data are shared with reflect an area for improvement?

### Observations

- **NOCs** - as a minimum, the individual CRA platforms should allow a NOC created/updated on one system to be created/updated on the others (a 'NOC TUO' approach). It would also be helpful to explain to consumers if NOCs containing potentially sensitive data (such as that relating to addiction or disability) might be shared with non-creditor organisations (e.g. such as landlords, letting agents, or potential employers)?
- **PSR** - a 'future proofing' exercise should be undertaken to consider how calls for the PSR to be expanded to incorporate other types of non-energy/water organisation can be achieved without the customer losing control or oversight of their information.
- **SH** - with its concentration of financial services firms, SH should work to develop relationships with a multi-sector network (including energy, water, and telecoms) firms. This will, however, require sector stimulus from Ofgem, Ofwat, Ofcom, and the ICO.
- **VRS** - in future improvements, it would be helpful if VRS users could see and select which organisations their information is shared with. Letting users also select any support need from the complete 'VRS menu' (rather than from a smaller fixed list based on circumstance) would be a helpful addition. A planned 'VRS Passport' will reportedly allow users more control over which organisations see their data<sup>26</sup>.
- **Collaboration** - it would assist data portability and consumer understanding if standard wording or definitions were introduced to describe common support needs. Clearly, different sectors will have some unique support needs (e.g. PSRs record consumers lacking a sense of smell, as this is key re: gas leaks). But there will be support needs that are common across sectors (e.g. 'needs extra time' or 'cannot use phone') where a standard definition would make sharing, understanding, and acting on needs easier.

## Further information

Sector	% of respondents who report ever disclosing mental health condition or support needs to a firm (by sector)	Privacy notice
Notice of Correction (NOC)	<p>Transunion:  <a href="https://www.transunion.co.uk/consumer/credit-report-help/what-is-a-notice-of-correction-and-how-can-i-add-one-to-my-credit-report-if-needed">https://www.transunion.co.uk/consumer/credit-report-help/what-is-a-notice-of-correction-and-how-can-i-add-one-to-my-credit-report-if-needed</a></p> <p>Experian:  <a href="https://www.experian.co.uk/consumer/guides/notice-of-correction.html">https://www.experian.co.uk/consumer/guides/notice-of-correction.html</a>   <a href="https://www.experian.co.uk/consumer/help-discover/discover/guides/gambling-credit-protection.html">https://www.experian.co.uk/consumer/help-discover/discover/guides/gambling-credit-protection.html</a></p> <p>Equifax:  <a href="https://help.equifax.co.uk/EquifaxOnlineHelp/s/article/What-is-a-Notice-of-Correction">https://help.equifax.co.uk/EquifaxOnlineHelp/s/article/What-is-a-Notice-of-Correction</a></p>	<p><a href="https://www.transunion.co.uk/legal/privacy-centre">https://www.transunion.co.uk/legal/privacy-centre</a></p> <p><a href="https://www.experian.co.uk/privacy/privacy-policies">https://www.experian.co.uk/privacy/privacy-policies</a></p> <p><a href="https://www.equifax.co.uk/privacy-hub">https://www.equifax.co.uk/privacy-hub</a></p>
Priority Service Register (PSR)	<a href="http://thepr.co.uk">thepr.co.uk</a>	<a href="https://www.energynetworks.org/privacy-policy">https://www.energynetworks.org/privacy-policy</a>
Support Hub (SH)	<a href="https://supporthub.experian.co.uk/">https://supporthub.experian.co.uk/</a>	<a href="https://supporthub.experian.co.uk/privacypolicy/welcome">https://supporthub.experian.co.uk/privacypolicy/welcome</a>
Vulnerability Registration Service (VRS)	<a href="http://vulnerabilityregistrationservice.co.uk">vulnerabilityregistrationservice.co.uk</a>	<a href="https://www.vulnerabilityregistrationservice.co.uk/privacy-policy/">https://www.vulnerabilityregistrationservice.co.uk/privacy-policy/</a>

## **2. Death and bereavement**

## 2. Death and bereavement

At the outset, we must recognise that unlike other uses of TUO, the ‘user control and choice’ principle may be less important when it comes to bereavement and death notifications.

Rather than valuing control over the organisations that information is shared with, people may instead prioritise the closure of as many of the deceased person’s accounts as possible.

Consequently, in the case of death, people may value a ‘Tell As Many’ option more than a selective ‘Tell These Ones’ approach<sup>1</sup>. And while not always technically possible to deliver, this illustrates the importance of nuance and context when talking about ‘TUO’ approaches.

Keeping this in mind, the review identified five TUO initiatives in the bereavement space:

- **Death Notification Service (DNS)** - run by Equiniti, this allows people to notify 48 financial service organisations (including insurers) about a person’s death without charge.

Strengths: offers a straightforward notification process, with online and phone options.

Considerations: primarily focused on financial service organisations.

- **Government Tell Us Once Service (GTUOS)** - this allows people in England, Wales, or Scotland (but not NI) to notify a death to multiple Government departments or agencies.

Strengths: an access code for GTUOS is given as part of the official registration of a death, so notified organisations should not require any further evidence to verify the death.

Considerations: does not collect the support needs/adjustments of the person notifying the death, so any subsequent Government interactions do not take these into account.

- **Life Ledger (LL)** - paid online service (with phone support) allowing people to reportedly notify over 1000 companies about a person’s death.

Strengths: clear explanations on how data are shared, who with, and for what purpose.

Considerations: there does not appear to be an accessibility policy or statement on the LL platform, nor is specific functionality for disabled customers referred to.

- **Settld (SD)** - free online service (with telephone support) operated by Estate Registry allowing people to notify a reported 1400 organisations across multiple sectors.

Strengths: the SD journey allows the user to notify organisations not only about the deceased person, but also about any relevant support needs that the user has as well.

<sup>1</sup>We would welcome being informed about use-cases/scenarios where such a ‘Tell Them All’ option would not be preferred.

Considerations: again, there does not appear to be an accessibility policy or functionality. Further information: the Estate Registry also operate the **Notify Now** TUO initiative. The key difference from SD appears to be that people must be referred by a firm or legal professional to NN (and users cannot initiate access to the product themselves).

The screenshot shows the homepage of the EQ death notification service. At the top left is the EQ logo and the text "death notification service". On the right is a link for "Accessibility Help". Below these are five yellow buttons: "Create an account", "Submit Death Notification", "Log in to your account", "Who Can I Notify?", "FAQ's", and "Useful Links & Support". A section titled "As featured in" displays logos for Which?, Daily Mail, THE GAZETTE (OFFICIAL PUBLIC RECORD), Good Housekeeping, YourMoney.com, The Telegraph, and THE TIMES. Below the logos, the text "The Death Notification Service" and "About the service" is visible.

The screenshot shows the "Tell Us Once" form for finding death registration details. At the top left is a "< Back" link and at the top right is an "Exit" link. The main heading is "Find death registration details". Below this is a grey box with the text: "If you need to go back to an earlier page, you will need to use the back links at the top of each page in this service. The back button in your web browser will not work." The form contains three sections: "Your Tell Us Once reference number" with a text input field and a note that it is 12 digits and a mix of numbers and letters; "Surname of the person who's died" with a text input field; and "What date did they die?" with a note "For example, 21 8 2024" and three input fields for Day, Month, and Year. At the bottom left is a green "Find details" button.

## **2a. What is their purpose?**

All five TUO initiatives help people notify multiple organisations about a person's death. However, differences exist in terms of sector coverage and reach.

The GTUOS shares data with a number of Government departments/agencies including HMRC, DWP, DVLA, Passports, Local Councils, Ministry of Defence, Social Security Scotland, and public sector pension schemes.

The DNS allows people to notify 48 financial service organisations (including insurers) about a person's death, with these covering many national and 'high-street' brands.

Meanwhile, LL, SD, and NN all report being able to notify over 1000 different organisations in energy, water, telecoms, and financial services. This includes some (but not all) of the financial services covered by DNS. They do not notify Government departments (due to the GTUOS).

## **2b How can they be used?**

The GTUOS offers online, telephone (including Relay UK), video services (for BSL users), and in-person notification. To access these, people use a reference number (active for 28 days) which is received on registration of the death along with a death certificate from the registrar.

All four other TUO initiatives provide online notification services, with the DNS also offering online and telephone notification. SD and NN offer a telephone help line (as well as digital), while LL provides an email/digital help service.

The DNS allows users to view the organisations they have notified (and within 90 days of this first submission, people can add and notify more organisations). Similarly, LL, SD, and NN allow the person to return and add, revise, or share information with more organisations.

## **2c. What is the degree of user control?**

As noted, 'choice' may be less important to people when it concerns which organisations are notified about a person's death, and which are not.

However, the DNS, LL, SD, NN, and GTUOS do ask people to select which organisations they want to notify. Users can therefore select every organisation on the list offered by a TUO initiative, although this may require manually selecting each organisation one-by-one.

## **2d. How are they designed?**

The DNS highlights keyboard and screen-reader accessibility features to its users, while GTUOS offers Relay UK and BSL video access. LL, NN, and SD did not appear to spotlight or point to accessibility features for its users.

**Life Ledger** About us Personal Business FAQs Login [Get started now](#)

# Close, freeze or transfer all of your loved one's accounts from one place.

Our easy-to-use death notification service can help you notify over 1,000 companies across the UK of a death.

[Start telling companies now](#)

As seen in

**Settld.** A Service of The Estate Registry Who we notify Checklist Settld User Reviews Resources Contact Us Login

# Reduce the stress, cost and time of bereavement admin.

When a loved one dies, use Settld to close or transfer their accounts in one go, fast-track probate, sell the property - and much more. One award-winning service to turn to, for saved time and peace of mind.

[Use Settld](#) It's free!

As featured in:

**BBC** **Which?** **METRO** **GOOD HOUSEKEEPING** **Forbes**

Read our [TrustPilot](#) and [user reviews](#)

## 2e. Summary recommendations

All five initiatives aim to simplify the complex events that can follow a person's death.

The **DNS** has a large footprint in financial services. Consequently, expanding to other sectors outside of financial services would represent a natural next step to take.

The **GTUOS** is the most established and probably well-known TUO approach in any sector (and possibly in terms of accessible design and range of contact channels offered too). But could it

become even more accessible by collecting any support needs the person notifying the death has, so any further interactions with Government about the death (or at a later point with the notifying individual) take these into account?

**LL** has many unique features (including a 'vault' where people - during their lifetime - can store key documents to make notifications after their death easier). However, could it improve the visibility/range of accessibility features in its product for disabled users?

The **SD** and **NN** initiatives have good reach, as well as capturing any support needs that a person may need help with themselves during the notification process. But again, can it improve the visibility/range of accessibility features in its product for disabled users?

### Observations

- The **DNS** should consider expanding to organisations outside of financial services.
- The **GTUOS** should collect any support needs or adjustments of those notifying a death, so that any future interaction about the death immediately takes these into account.
- The **LL**, **SD**, and **NN** initiatives should review how they can improve the visibility/range of accessibility features in its product for disabled users.
- **Collaboration** - if the different TUO initiatives were to collect information on the support needs of a those notifying a death, then standard lists or definitions should be employed.

Name	Main sites	Privacy notice
Death Notification Service (DNS)	<a href="https://deathnotification.service.co.uk">deathnotification.service.co.uk</a>	<a href="https://www.deathnotificationsservice.co.uk/Privacy_policy.ofml">https://www.deathnotificationsservice.co.uk/Privacy_policy.ofml</a>
Government Tell Us Once Service (GTUOS)	<a href="https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once">https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once</a>  <a href="https://tell-us-someone-died.dwp.gov.uk/idp/Death/Enrich/BeforeYouStart?">https://tell-us-someone-died.dwp.gov.uk/idp/Death/Enrich/BeforeYouStart?</a>	<a href="https://tell-us-someone-died.dwp.gov.uk/privacystatement.html">https://tell-us-someone-died.dwp.gov.uk/privacystatement.html</a>
Life Ledger (LL)	<a href="https://lifeledger.com">lifeledger.com</a>	<a href="https://lifeledger.com/privacy-notice/">https://lifeledger.com/privacy-notice/</a>
Settld (SD)	<a href="https://settld.care">settld.care</a>	<a href="https://www.settld.care/settld-privacy-policy-2/">https://www.settld.care/settld-privacy-policy-2/</a>

## **3. Health and social care**

### 3. Health and social care

So far, our review has described TUO approaches that share data digitally.

However, in this section, alongside digital sharing initiatives we introduce a different approach: **physical resources** that communicate information about a person when presented or consulted.

Physical media meet our TUO criteria where through a single resource, people can share information (such as support or communication needs) with multiple organisations or teams.

One such physical 'TUO' resource was found in our review of the health and social care sector:

- **This is Me (TiM)** - Alzheimer's Society tool for people with dementia to share personal information and support needs not found on a formal clinical/social care record.

Strengths: captures free-text information in a short paper or editable PDF (owned by the person) that brings the individual to the foreground and informs person-centred care.

Considerations: paper-based with editable PDF (that can be emailed), but with no digital portal or distribution system to support it. Relies on the person sharing the record.

We also identified three other TUO health and social care approaches:

- **About Me (AM)** - NHS England data standard that records key information (under seven broad headings) patients want to share about themselves with professionals or carers. While the person can create and own this digital record (e.g. via a personal website or resource, with a weblink being placed in their official record for professionals to access), in practice it is more likely this information will be recorded by a professional.

Strengths: like TiM, it can be created by the person. It can be shared digitally, and include audio, images, videos and other personal information that is relevant to their care.

Considerations: reports that AM is not widely shared across health/social care sector.

- **Accessible Information Standard (AIS)** - this is an NHS England standard for NHS or social care providers to identify, record, flag, share, meet, review, and update patient information or communication needs (with data stored in a structured standard).

Strengths: support needs and adjustments are defined and recorded in structured format by the AIS, and needs recorded with one provider should be shared across the system.

Considerations: no online portal for users to create an AIS record, with AIS embedded in different platforms and systems (including digital and some paper-based approaches).

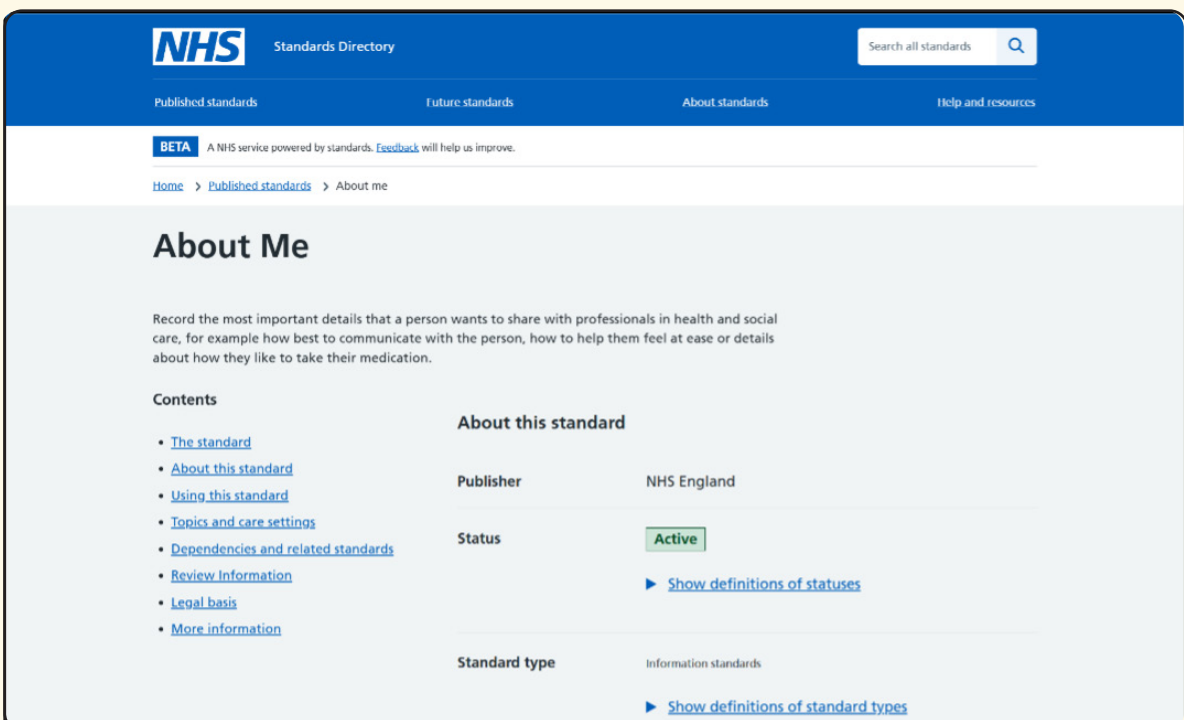
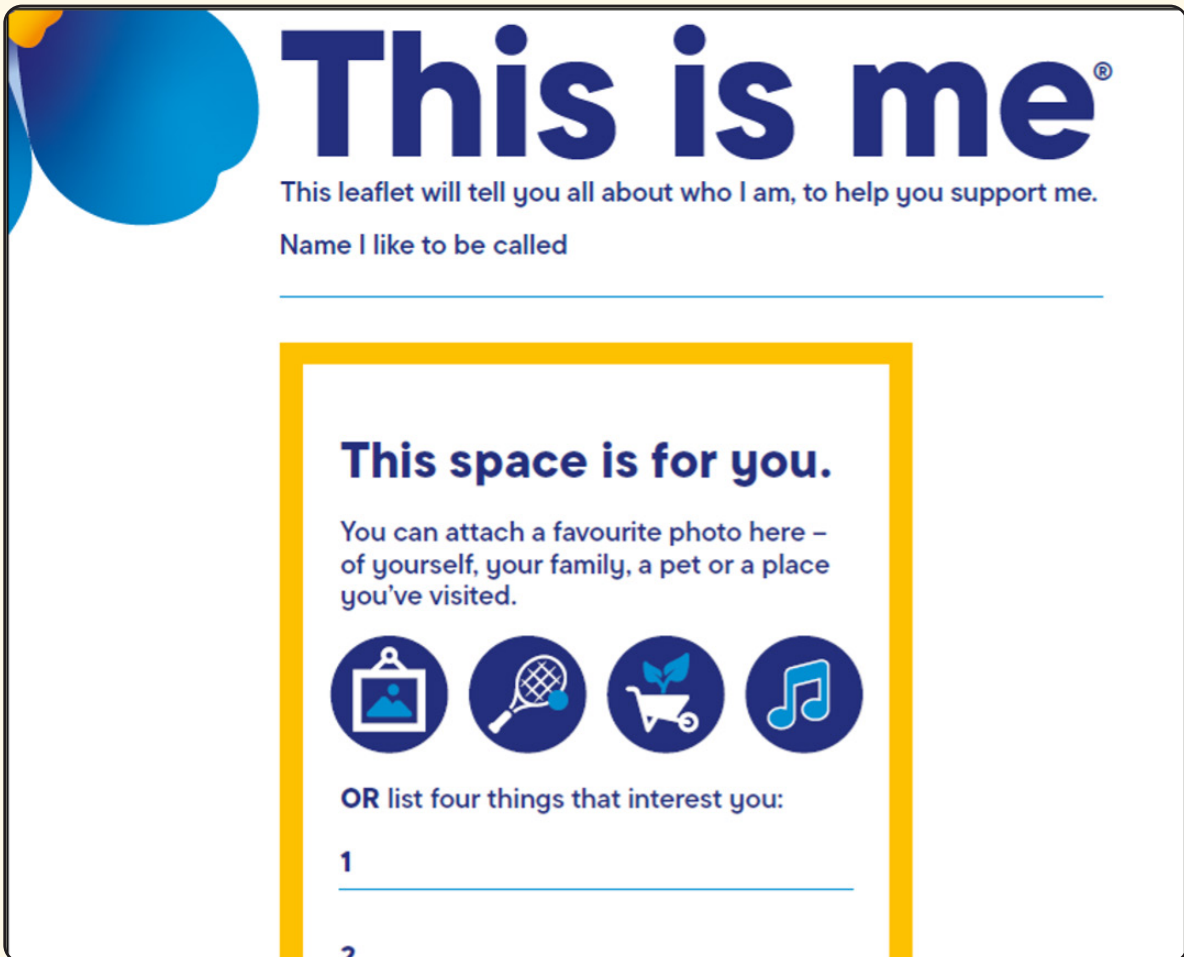
- **Universal Care Plan for London (UCP)** - tool to share care preferences with professionals.

Strengths: patients (via NHS log-in) or health/care professionals (after patient contact)

can use the UCP to record wishes and preferences in a personalised care plan. This plan is

accessible across multiple record systems, enabling coordinated care planning.

Considerations: patients can update non-clinical sections (such as “what matters to me”), but clinical information must be completed by a health or care professional.



### **3a. What is their purpose?**

TiM and AM have the same purpose: to enable individuals to share a far more personalised and detailed account of themselves (including support needs and preferences, but also free-text personal histories and interests) that would not normally feature in official clinical/care records.

Designed to be used alongside formal care plans, TiM focuses on helping hospitals, care homes or professional care providers in a home care environment provide a personalised service (and can also be shared/emailed with other agencies). AM has a similar approach, but like TiM its sharing across health/social care has been reported as constrained.

The AIS and UCP take a more structured approach to recording TUO data. The AIS points to existing NHS coded information ('value-sets') for reasonable adjustments (such as SNOMED-CT). Meanwhile the UCP is comprised of multiple forms containing structured questions that relate to issues such as users' advance decisions, power of attorney, and preferred place of death (recorded using OpenEHR standards, as well as a smaller number of fields using SNOMED-CT).

### **3b. How can they be used?**

Compared to the essential services sector, fewer online 'self-service' options were identified.

Neither TiM or AM offer an online self-service portal for people to create or update the information they wish to share. TiM is a paper or editable PDF resource (which means it can be shared via email or printed copies). Meanwhile AM relies on users (or those supporting them) creating their own digital resource, website, or Wiki.

Both AM and AIS should be incorporated into core patient information held by the NHS. Therefore, data recorded with AM and AIS by one provider should be available to others in the NHS. This makes it a vehicle for TUO, albeit one without a dedicated user-portal or interface.

In contrast, the UCP is already viewable in the NHS App (to registered users in London), and the ability for users to edit the non-clinical sections of the record will be introduced shortly.

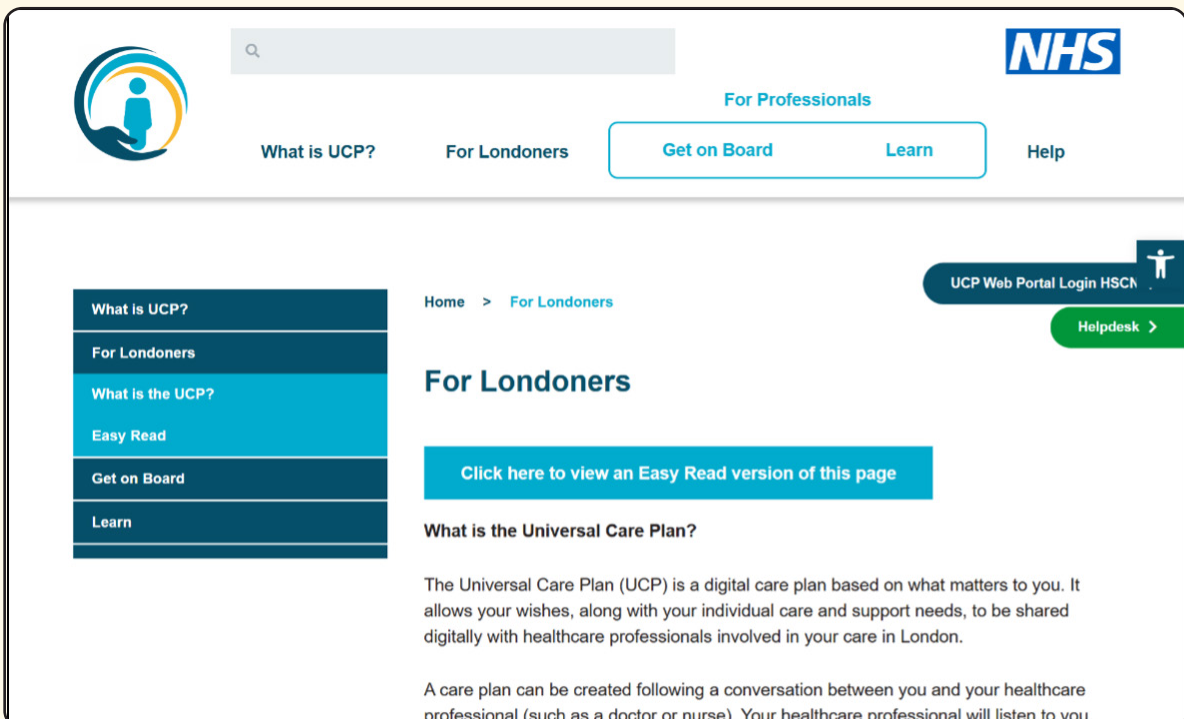
### **3c. What is the degree of user control?**

TiM and AM offer high levels of user control (the former as a physical/PDF booklet, and the latter as a user-created record) and can therefore be edited and updated. However, as neither are directly stored in a wider distribution system, they could be overlooked or not consulted.

The AIS and UCP can be updated, but this can only happen where users contact a service or professional and ask them to make changes (although UCP users will shortly be able to edit their record via the NHS app shortly), or when a professional routinely reviews/updates the record.

### 3d. How are they designed?

The UCP was the only fully integrated, viewable, and (shortly) user-controlled option identified. The TiM is designed by the voluntary sector, while the use of AM and AIS depends on the systems they are incorporated into across the NHS and/or social care.



### 3e. Summary recommendations

All four initiatives aim to better personalise care and support within health and social care.

**TiM** is a simple paper and PDF based TUC resource for people either living with dementia or with communication difficulties. However, as with any physical TUC tool, the question is whether it should become digital too?

In contrast, **AM** is designed to be a digital resource. Furthermore, as an NHS England data standard, it is embedded in other NHS data standards (such as the Core Information Standard). However, does the lack of a dedicated online portal limit its take-up? And is its reach limited by a potential lack of interoperability between health and care systems?

The **AIS** draws on a standard NHS language for classifying and recording patients' information and communication support needs arising from disability. But is there a way for users to update or control these needs on the platforms that use it without doing this through a healthcare service or professional?

The **UCP** represents a positive initiative that serves London (and again, is probably an example of other schemes operating regionally that the review did not identify). However, in the future, could it provide a way to update or manage the support needs offered on the AIS?

#### Recommendations

- **TiM** may not see a reason to 'go digital' given it can already be edited/shared via email. However, as a paper-based resource, it could still include support needs for interactions outside of hospital/care settings (such as with other services or in public settings).
- **AM** offers a TUC approach that could be controlled by its users - however, more should be done to promote the option for creating content via third-party wikis, or through a centralised resource such as the NHS app.
- The **AIS** could review the support needs met by other sectors (such as common essential services) to establish if any additional needs could be added to its data-set.
- The **UCP** should ensure that when professionals talk with patients to create a 'universal plan', they also capture communication needs that align with the structured AIS record.
- **Collaboration** - again, it would assist data portability and user understanding if standard definitions were employed to describe the same support needs. Therefore, in the same way that organisations outside of the health and social care sector should review the AIS need set, the AIS and NHS should consider what can be learnt from other sectors too. Additionally, the AM and the AIS also need health and social care professions to make a further effort to promote these initiatives to patients, share the resulting data across systems, and act on this information once it has been recorded and shared.

## Further information

Name	Main sites	Privacy notice
This is Me (TiM)	<a href="https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me">https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me</a>	N/A
About Me (AM)	<a href="https://standards.nhs.uk/published-standards/about-me">https://standards.nhs.uk/published-standards/about-me</a>	N/A
Accessible Information Standard (AIS)	<a href="https://www.england.nhs.uk/accessible-information-standard/">https://www.england.nhs.uk/accessible-information-standard/</a>	N/A
Universal Care Plan London (UCP)	<a href="https://ucp.onelondon.online/">https://ucp.onelondon.online/</a> <a href="https://ucp.onelondon.online/patients/">https://ucp.onelondon.online/patients/</a>	<a href="https://ucp.onelondon.online/wp-content/uploads/2022/08/Better-UCP-Privacy-Notice-Direct-Care-v1.1.docx.pdf">https://ucp.onelondon.online/wp-content/uploads/2022/08/Better-UCP-Privacy-Notice-Direct-Care-v1.1.docx.pdf</a>

## **4. Retail, leisure, and transport**

## 4. Retail, transport, and leisure

The value of a well-designed TUO approach not only exists in relation to our interactions with utilities, dealing with life events like bereavement, or use of public bodies like the NHS.

TUO initiatives can also help disabled people, or those with additional support needs, to buy a washing machine, travel on public transport, or book and enjoy a concert, just like anyone else.

Consequently, the development of TUO approaches in retail, transport, and leisure is as important as any other sector. Here our review identified five initiatives:

- **Hidden Disabilities Sunflower (HDS)** - physical resource (lanyard and card), 'tappable' NFC card (Sunflower Extra), and digital tool (app) to indicate/share non-visible disabilities.

Strengths: well-known scheme, widely recognised branding, and simple registration.

Considerations: the HDS scheme is primarily designed for in-person situations and interactions, and only partially covers phone, written communication, or other channels.

- **Just A Minute Card (JAMC)** - mostly used in Northern Ireland/ROI, this is a card and app that allows disabled customers to ask for 'Just A Minute' of extra patience and support.

Strengths: easy to apply for and use.

Considerations: the information shared on the JAM card is mostly about diagnosis and condition, and the only actionable support need it offers is to ask for 'more time'.

- **Access Card (AC)** - the AC was developed by Nimbus to evidence and show a customer's disability and support needs at entertainment venues and leisure settings.

Strengths: well-recognised and accepted by many live music and performance venues.

Considerations: customers must provide suitable evidence of a disability to obtain an AC. Support needs relate to venue experience, not online/telephone purchase of tickets.

- **Passenger Assistance (PA)** - an app and website allowing disabled customers to request support and assistance for rail journeys, and to receive confirmation of their booking

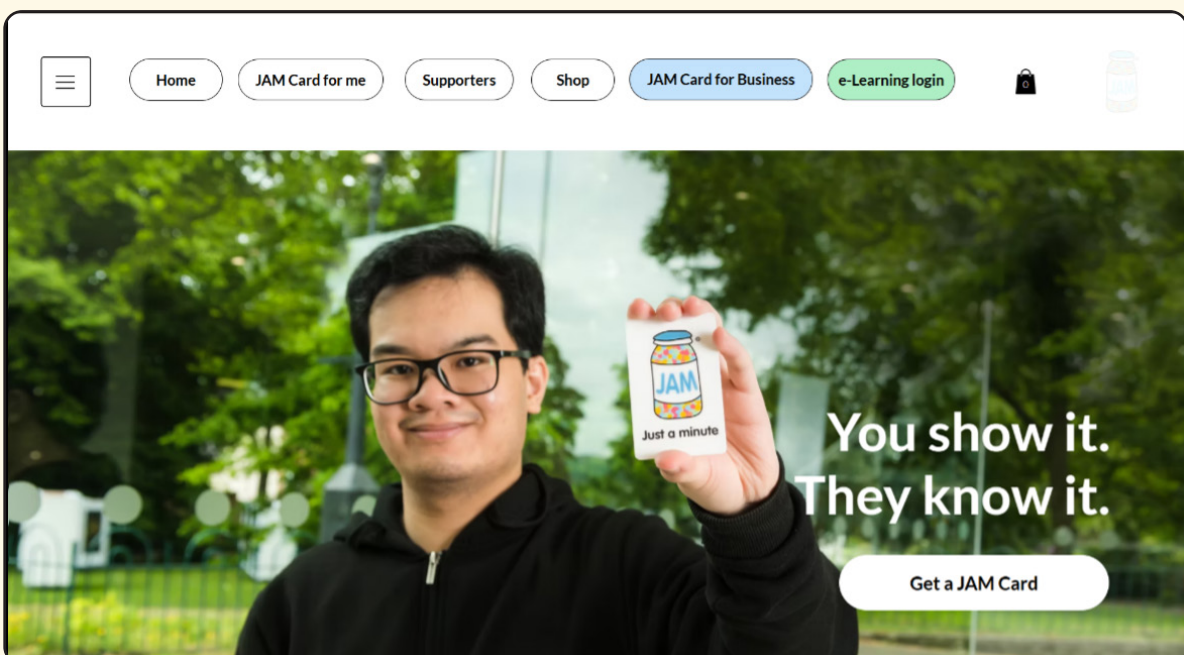
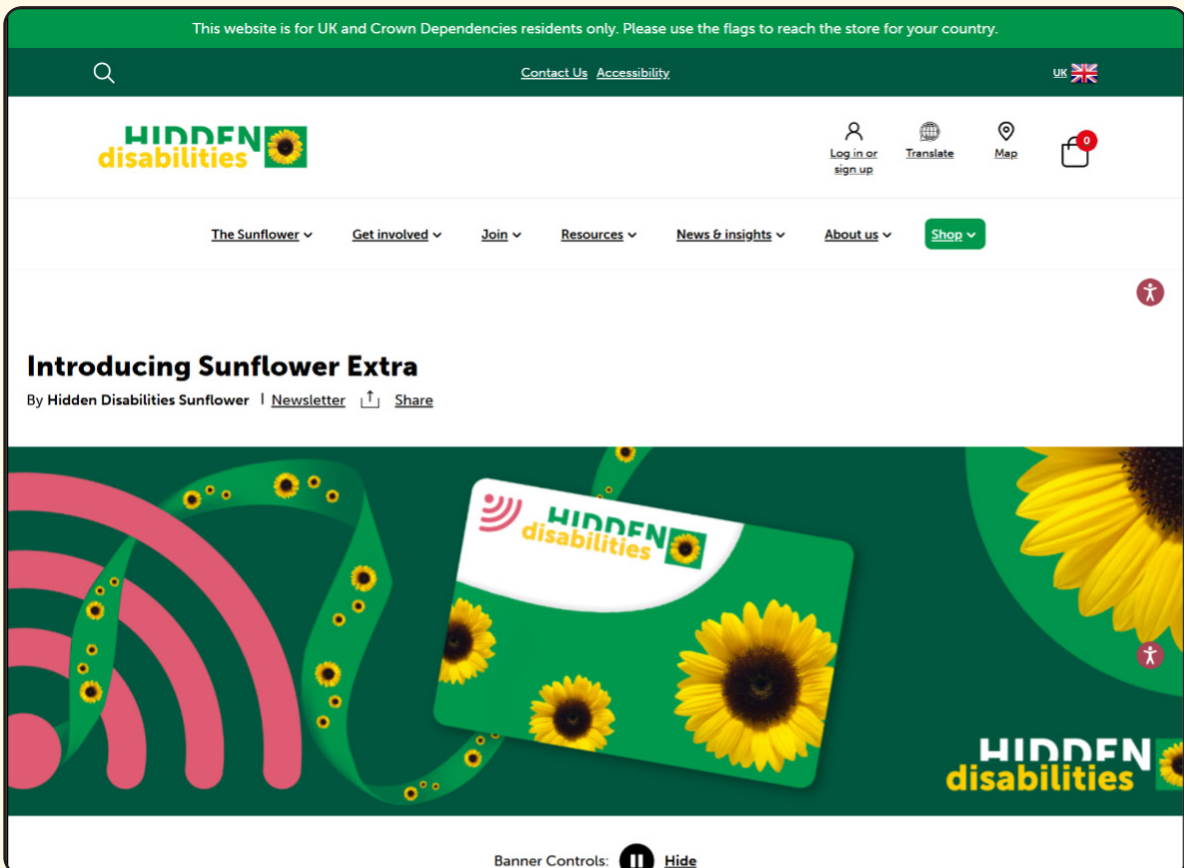
Strengths: covers 13 support needs with free-text box to supply additional information

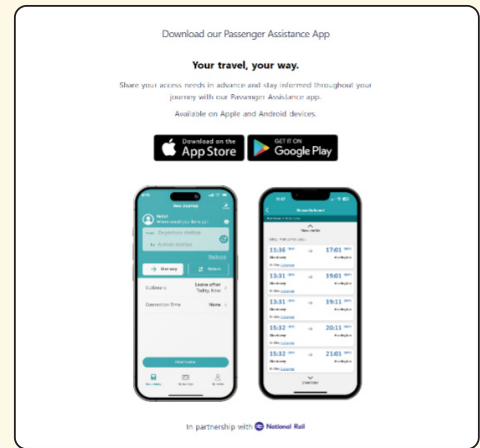
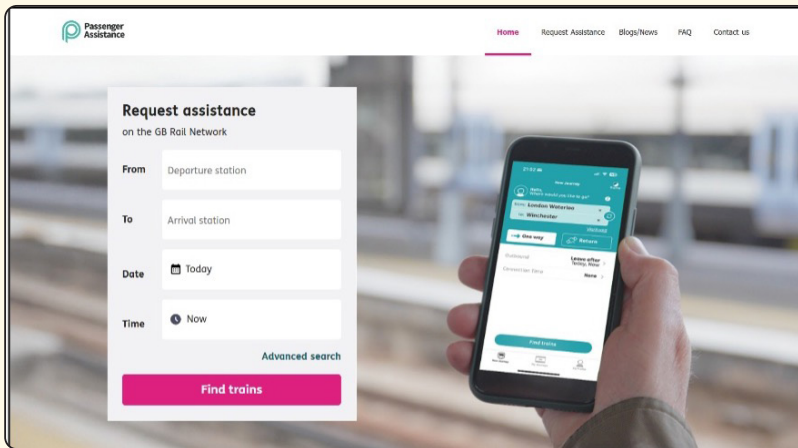
Considerations: covers train operating companies (and not other transport providers), and - like all TUO approaches - trust in the system depends on needs being consistently met by the companies receiving the information.

- **WelcoMe (WM)** - platform where (a) users share access needs in advance of a visit to a participating venue, and (b) staff welcoming the user get ‘tips’ on meeting these needs.

Strengths: well-designed, transparent privacy information, and list of support needs for each participating venue can be select from.

Considerations: list of participating venues is still growing (gaps exist in venues offered). Online tool only and support needs are primarily in-person rather than other channels.





#### 4a. What is their purpose?

The HDS and JAMC share the same purpose: to publicly signal that the holder may require extra time or support. The JAMC does this through displaying (on the card or app) a simple message (“Please be patient. I have [name of condition]”). Meanwhile, the HDS communicates additional information (via symbols and written text) on what that support might be.

When worn/shown, the AC can indicate that a person has additional support needs, as well confirming that the person has a disability (as AC holders have to show evidence of a disability when applying). The PA tool simplifies requests for support during rail journeys, while the WM platform lets users share needs with venues in advance of a visit.

#### 4b. How can they be used?

The HDS, JAMC, and AC offer plastic cards. The HDS and JAMC can be worn in purchasable ‘sunflower’ or ‘jam jar’ decorated lanyards, and the JAMC can be posted for free to customers. While all need to be ordered online, the actual TUO cards can be used in a non-digital way.

The HDS also offers a ‘Sunflower extra’ card which uses NFC technology to allow information on the card about a customer’s disability and support needs to be ‘tapped and read’ by staff in participating venues (avoiding customers having to re-notify or explain this aloud in public).

The JAMC offers an additional app (where its simple message can be shown on a phone screen). All five TUO initiatives (including PA and WM) require the customer to use a website to either register or share their needs, with no evidence of offline alternatives.

#### 4c. What is the degree of user control?

The HDS, JAMC, and AC offer a high degree of control as users can choose when (and whom) they display their lanyard or card to. WM supports user choice, as users can share conditions or diagnoses as they wish. The PA tool allows users to select their support needs.

#### 4d. How are they designed?

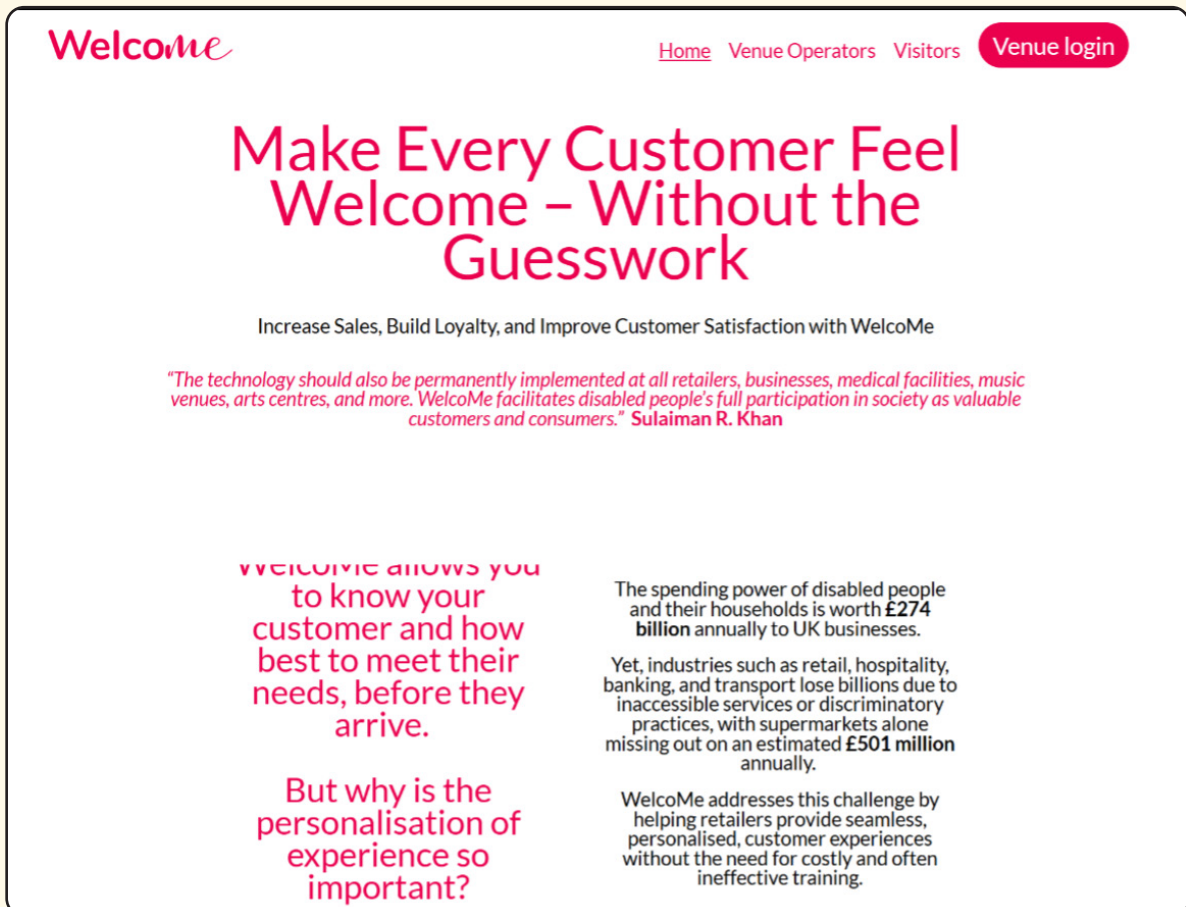
All online platforms - as might be expected given the purposes of the TUO cards or initiatives being reviewed - appear to be designed with accessibility in mind.



**HAVE YOU GOT YOUR ACCESS CARD?**

Get your access requirements recognised at thousands of events, attractions, venues, and locations across the UK and beyond.

The image shows a sample 'ACCESS CARD' for Jack Rowland, ID Number 271556, with an expiry date of 27/000/2026. The card includes a photo, a QR code, and icons for accessibility needs such as a wheelchair, a dog, a hearing aid, a white cane, a +1, and a WC. Below the card, a network of icons is connected by dotted lines, representing the wide range of venues and events where the card is accepted.



**Welcome** [Home](#) [Venue Operators](#) [Visitors](#) [Venue login](#)

## Make Every Customer Feel Welcome – Without the Guesswork

Increase Sales, Build Loyalty, and Improve Customer Satisfaction with WelcoMe

*"The technology should also be permanently implemented at all retailers, businesses, medical facilities, music venues, arts centres, and more. WelcoMe facilitates disabled people's full participation in society as valuable customers and consumers." Sulaiman R. Khan*

**WELCOMe allows you to know your customer and how best to meet their needs, before they arrive.**

**But why is the personalisation of experience so important?**

The spending power of disabled people and their households is worth **£274 billion** annually to UK businesses.

Yet, industries such as retail, hospitality, banking, and transport lose billions due to inaccessible services or discriminatory practices, with supermarkets alone missing out on an estimated **£501 million** annually.

WelcoMe addresses this challenge by helping retailers provide seamless, personalised, customer experiences without the need for costly and often ineffective training.

#### 4e. Summary recommendations

All five TUO initiatives are focused on in-person interactions.

As they are specifically for in-person situations, this means the initiatives are either only partially designed to cover telephone, written communication, and other channels, or not at all.

While the initiatives are designed to communicate a user's situation or support needs, it was not clear whether information from the AC, WM, or PA was simply viewed by an organisation, or if it was then also recorded on that organisation's own internal system. The HDS Sunflower extra card displays a user's situation/support needs when read, but this is only temporarily visible and cannot be recorded by organisations on their own system.

The **HDS** lanyard and card is possibly the TUO approach with the best public visibility and profile. However, while users can add their own short written statement describing their specific needs in more detail, could it offer a wider range of 'core' support needs than the current set of 25?

The **JAMC** is the simplest and easiest to use TUO approach. However, could this be a limitation, as users cannot state/share any specific support need (and are restricted to 'Please be patient')?

The **AC** card allows customers to evidence their disability to an entertainment or leisure venue. However, it would be useful to know if the AC card might not only cover experience inside the venue, but also be expanded to cover the online/phone purchase of tickets preceding this?

The **PA** initiative allows customers to request assistance for rail journeys (and to receive confirmation). However, could it be expanded to other forms of public transport (as well as addressing user reports of assistance requests not being met)?

The **WM** platform lets users share their support needs in advance of a visit to a participating venue. In the short-term WM also gives venue staff 'pre-meeting tips' to support the customer, and a longer-term option of receiving 'refresher' training to maintain skills. However, as with all TUO 'in-person' initiatives, can it recruit more venues to meet user need across the UK?

#### Observations

- **HDS** should consider expanding its core set of actionable support needs.
- **JAMC** could let users communicate specific support needs (not just a simple message).
- **AC** might cover the online/phone purchasing of tickets, as well as in-venue experience.
- **PA** should explore its responsiveness and expansion to other forms of public transport.
- **WM** should continue to add to its list of participating venues and supporting staff.
- **Collaboration** - again, it would assist data portability and understanding if standard definitions were used to describe the same support needs. In this case, just as organisations outside of the retail and leisure sector should learn from the approach taken here, so too could organisations listed here learn from other sectors.

## Further information

Name	Main sites	Privacy notice
Hidden Disabilities Sunflower (HDS)	<a href="https://hdsunflower.com">hdsunflower.com</a>	<a href="https://hdsunflower.com/uk/insights/post/introducing-sunflower-extra">https://hdsunflower.com/uk/insights/post/introducing-sunflower-extra</a>  <a href="https://hdsunflower.com/uk/privacy-notice">https://hdsunflower.com/uk/privacy-notice</a>
Just A Minute Card (JAMC)	<a href="https://www.jamcard.org">jamcard.org</a>	<a href="https://www.jamcard.org/privacy-notice">https://www.jamcard.org/privacy-notice</a>
Access Card (AC)	<a href="https://www.accesscard.online">accesscard.online</a>	<a href="https://www.accesscard.online/legal/privacy/">https://www.accesscard.online/legal/privacy/</a>
Passenger Assistance (PA)	<a href="https://passengerassistance.com">passengerassistance.com</a>	<a href="https://passengerassistance.com/privacy-policy/">https://passengerassistance.com/privacy-policy/</a>
WelcoMe (WM)	<a href="https://key.wel-co.me">wel-co.me</a>	<a href="https://key.wel-co.me/privacy-policy">https://key.wel-co.me/privacy-policy</a>

## **5. Workplace and higher education**

## 5. Workplace and higher education

The workplace and higher education are settings in which awareness about support needs and reasonable adjustments is arguably well established (if not always translated into action).

However, in our review, this enhanced level of awareness was not matched by the number of TUO approaches identified, with only two initiatives being encountered:

- **AXS passport (AP)** - an online tool letting users share 240 support needs and reasonable adjustments with multiple organisations for interviews, work, education, or events.

Strengths: users can create multiple support need 'passports' which can be shared with different organisations (recognising that a user's needs may differ by environment), and an AI chatbot 'Rosa' can suggest needs based on user descriptions of their situation.

Considerations: profiles can be shared with any organisation, but only if a user has an email address to send the profile to. Receiving organisations will also need an AXS account/licence to integrate the data into their system (otherwise it is 'view only').

- **Health Adjustment Passport (HAP)** - a paper-based or digital document (in PDF and ODT format) provided by the DWP to help disabled jobseekers and employees identify, record, and communicate their support needs to employers and Access to Work scheme.

Strengths: serves as a portable record that moves with the individual between different roles or employers, and to help lead structured conversations about reasonable adjustments from the interview stage onwards.

Considerations: lacks the interactive or automated features of integrated digital platforms and relies on the user to manually update/proactively share the information.

### 5a. What is their purpose?

The AXS passport aims to be an 'open' TUO system where a user can share their support needs with any organisation that has an email address. On one hand, this represents a strength, as the AXS system does not require an organisation to be a subscriber to receive a user's passport. Additionally, the AXS system has an extensive list of support needs, including giving users the option to describe/supplement many of these needs with free-text descriptions.

However, this approach has limitations. Users may not be able to obtain an organisational email to send their passport to. And even if a passport can be emailed, the organisation receiving it may not be able to (a) view the data (due to internal IT/security control), (b) meet the requested needs (contrary to potential user expectation), or (c) record the needs on their own internal system (due to incompatibilities between the passport format and how an organisation may routinely define and record its own support need data<sup>1</sup>).

<sup>1</sup>Some essential service firms have decided not to record free-text information about support needs in order to minimise the risk of storing large amounts of personal data, rather than more manageable flags or support need indicators.

## Inclusion doesn't happen by default. It happens by design.

AXS Passport gives your organisation the tools to deliver workplace adjustments – at scale, with care, and backed by real data.

[Sign in or register →](#)



## Your Health Adjustment Passport

### Other ways to communicate with us

If you need braille, British Sign Language, a hearing loop, translations, large print, Easy Read, audio or something else, please contact us on 0800 169 0310.

If you use Relay UK dial 18001 followed by our telephone number.

If you live in Wales and want this form in Welsh call 0800 328 1744.

This passport can be used if you have a disability or health condition that makes it harder for you to move into work or stay in a job. This passport can be used to:

- support you to identify what support and changes (known as reasonable adjustments) you may need when you are in work or moving into work
- help you to apply for support from Access to Work. This could include funding for specialist equipment to support you to do your job, support getting to and from work or support when you are in work, such as job coaching
- help you talk to employers about adjustments and in-work support that you may need.
- A job could also include, self-employment, an apprenticeship, work experience or a supported internship.

This passport belongs to you and it cannot be shared with others without your permission.

### About you

<p><b>01</b> Your surname or family name</p> <input type="text"/>	<p><b>05</b> What type of work would you like to do?</p> <input type="text"/>
<p><b>02</b> All other names in full</p> <input type="text"/>	

The Health Adjustment Passport (HAP) is designed as a portable, person-centred record to help individuals identify and articulate the support they need to start, stay in, or move between jobs. Aiming to help facilitate a conversation between an individual and employer (or prospective employer) about reasonable adjustments, it also provides a resource to submit information to the Department for Work and Pensions (DWP).

Essentially a form that can be shared with multiple prospective/current employers, the TUO element of the HAP comes from its aim to remove the need to redisclose support needs to each employer in turn. Consequently, its effectiveness relies on the receiving organisation, including whether it can be recorded and integrated into internal systems or workflows.

#### **5b. How can they be used?**

AP is an online platform. Once registered, users can create multiple passports to share with different types of services or organisational contexts (as support needs can differ across these). Each passport contains standard support need indicators or flags (that users select from a wider list), as well as the ability for users to provide additional free-text information about their needs.

HAP is a document resource which is either printed and filled-in by hand or completed as an editable digital document. This document can then be sent to prospective or current employers.

#### **5c. What is the degree of user control?**

The AP offers full choice and control over what is shared and with whom. HAP also offers a high degree of control. It remains the property of the user at all times, and as there is no central database or 'third-party' host, the user decides who sees the passport.

#### **5d. How is it designed?**

The AP initiative is well-designed. The user experience is further enhanced by the "Rosa" AI chatbot tool, which helps users identify support needs they may not be aware of. Its use of an 'email-able' passport also recognises that disabled people and those in vulnerable situations have relationships with a range of organisations, and do not live in specific 'sector silos'.

The HAP is designed around a structured, form-based approach. Data is presented in sections such as 'About me', 'My condition', and 'Adjustments at work'. Its design reflects a traditional civil service form (albeit one that can be shared with multiple prospective employers).

#### **5e. Summary recommendations**

The AXS passport introduces a different type of TUO model to our review. Users can select from a range of support needs, use the AI 'Rosa' chatbot to suggest adjustments to them, and send multiple passports to any organisation they have an email for. The HAP takes a similar approach but with a more traditional 'form design' being employed to share reasonable adjustments with prospective or existing employers.

For both passport approaches, however, questions exist about the extent to which organisations may be able to receive, process, and enact the support needs described by a user?

### Observations

- the **AP** should explore an offline alternative to its digital offering (to ensure it is accessible to as many users as possible).
- the **AP** could also improve (a) its passport format to overcome the difficulties that organisations may have in receiving it, and (b) user instructions about sharing a passport (to manage expectations about what a receiving firm may be able to do in response).
- the simplicity of the **HAP** is its greatest strength - however, its effectiveness relies on the receiving employer recording and integrating the HAP into internal systems or workflows. As with all TUO initiatives reviewed here, we would welcome any evaluation data from the DWP on the degree to which this happens.
- **Collaboration** - again, it would assist data portability and user understanding if standard definitions were used to describe the same person support needs across major TUO platforms (rather than using a unique language or definition).

### Further information

Name	Main sites	Privacy notice
AXS Passport	<a href="https://www.axspassport.com/">https://www.axspassport.com/</a>	<a href="https://www.axspassport.com/policies?policy=privacy">https://www.axspassport.com/policies?policy=privacy</a>
Health Adjustment Passport (HAP)	<a href="https://www.gov.uk/government/publications/health-adjustment-passport">https://www.gov.uk/government/publications/health-adjustment-passport</a>	N/A

## E. What should happen next?

### Tell Us Twenty

This review has identified 20 different TUO initiatives in the UK.

Delivering any TUO approach takes enormous effort, planning, and bloody-minded persistence. And the 20 initiatives reviewed here are -on-balance - making peoples' lives better.

So this represents impact that should not be swiftly dismissed or under-valued.

## **There is a 'but'**

Let's step back though from the 'mile-high' view of the different sectors we have reviewed.

And instead, let's ground ourselves in the daily life, circumstance, and experience of real people. People who may, at some time in their lives, need support from multiple services or sectors.

Now consider telling this person - at the height of their need - about the 20 TUO approaches. Each requiring registration, each talking about 'support' differently, and each with its own data sharing controls and features.

Would they conclude that TUO really exists?

## **So - what are we delivering?**

We currently have a **TUO archipelago** - scattered islands of divergent and unaware data activity. Designed to meet the needs of specific sectors, each works on its own TUO problem in isolation. This has resulted in an array of distinct models from which much can be learnt (Figure 6).

But in remaining unconnected from their neighbours, and without either bridges or a common language to share information, the over-arching problem remains intact and untouched: the need for people to repeatedly inform, notify, or disclose to the key organisations in their lives.

## **Broadly, what is needed then?**

At the outset, we do not believe a single TUO system - covering all major sectors - is feasible. Government interest, commercial appetite, and public trust do not exist for this. Instead, we need to allow data to more easily move between those TUO initiatives that do exist.

One way to achieve this is through collaboration between different TUO approaches or 'islands': data-sharing agreements, standard definitions of common support needs (for data portability), and - critically - user control over who sees their data will be key to this.

However, if TUO providers prefer isolation to collaboration, the Data (Use and Access) Act 2025 offers another option: the strengthened right for people to instruct a company to send the information it holds about them to another company. Such 'data portability' allows for **person created and controlled data-sharing** across services aided by digital wallets and identities.

## Figure 6: four models of TUO

From the 20 different TUO initiatives identified in the UK, four main models exist:

- **Disclose and delegate** - some TUO approaches collect and share user data for a specific purpose across a small number of organisations. Here users do not typically control who their data are shared with (or what is shared). Instead, the TUO initiative determines this, based on operational factors and what is in the 'best interests' of users.

Strengths: this recognises that some people do not want to get involved in choices about data-sharing, and want organisations to get on with sharing data for them.

Considerations: with a small number of organisations (particularly where these provide a similar service or product) it may be simple to identify what a user's 'best interests' are. However, as a larger number of organisations are added to a data-sharing arrangement (particularly where these organisations are diverse and do different things), how can a users' 'best interests' always be clear or known to everyone involved?

- **Disclose and dashboard** - other TUO approaches provide people with a higher level of choice over what data is shared with which organisations. Here dashboards are often used to present a person's previous data-sharing choices, and to help them manage any changes or updates to this.

Strengths: allows people to control many aspects of how their data are shared.

Considerations: many users may be willing to spend time in setting-up and managing such an arrangement, but then want a TUO approach to semi/fully-manage their data-sharing based on what is known about their previous preferences or choices.

- **Disclose and distribute** - here people share their situation/support needs with a central TUO provider, who then allows a larger number of organisations who meet eligibility criteria to (a) view this data and (b) in some cases, share data with other organisations they believe are eligible to do so. The person is made aware of these criteria but cannot control which organisations view the data, nor know which have viewed it.

Strengths: simple and straightforward form of data-sharing and distribution.

Considerations: the user does not control or know whom data are shared with.

- Disclose and display - these use physical resources (e.g. cards, booklets, lanyards) and/or digital media (e.g. phone-based apps) to quickly and visually communicate a person's circumstances or needs using symbols, summaries, or simple messages. The user may have to pre-disclose or prove their status/needs to a TUO provider to obtain a resource. Designed primarily for in-person interactions or physical environments.

Strengths: person chooses when and who to share this information with.

Considerations: may only cover certain needs, disabilities, or situations.

### Specifically, who should do what?

We end by making three recommendations - each with a responsible body for delivering them:

1. **the ICO must consider TUO approaches in their 'guidance for organisations' resources** -despite their prevalence and likely further growth in the UK, there is just a **single passing reference** to TUO approaches in the ICO's guidance for organisations.

Given the design choices and challenges that TUO approaches to data-sharing introduce, this lack of guidance does not align with the ICO's strategic ambition to "safeguard and empower the public, particularly vulnerable groups".

While an ICO code on data-sharing exists, this is more focused on general data-sharing arrangements between organisations, rather than considering the case of an organisation or business that has been specifically set-up to share the information of customers in vulnerable circumstances.

In particular, the issues of **individual control and transparency** have been shown to be the preferred 'default setting' of many disabled people as well as individuals in vulnerable circumstances, including (a) controlling and knowing which organisations their data are shared with and (b) being able to revise or revoke any data that has been shared (both with the TUO provider and any organisation receiving information from them).

2. **TUO systems in energy, water, and financial services should sign-post to one another** - we are not calling for a new initiative, unified database, or data-sharing flow. However, as a first step, we would like people completing a TUO journey with an energy or water firm being simply sign-posted to a TUO journey for financial services (and vice versa). Doing this would represent the building of the first bridge between the 'isolated islands' of TUO activity in these sectors, and a step that would practically help people.

3. **the Smart Data Council (chaired by Liz Lloyd, Minister for Digital Economy) should help create the conditions for standardised definitions of the most common support needs.**

The portability of person's data is key to the Government's digital and growth targets. Aiming to allow users to more easily obtain, collate, and use the information held about them by firms, this is likely to be a key driver for activity in the next decade.

Disabled people or those in vulnerable situations may not ask an organisation to send them data held about their support needs (as they already know this). But they could ask for it to be shared with another organisation or stored in a third-party wallet/identity.

And it is here, that a lack of standardised definitions of the most common support needs could hinder sharing. Given the range of definitions found in this review, organisations receiving such data may find it difficult to integrate this into their systems or workflows.

Standardised definitions of the most common support needs could help prevent this issue while making it easier for people to understand what different TUO systems offer.

### **Finally, what has this review missed?**

This review set-out to simply map and describe the TUO initiatives in operation in the UK today. However, like all studies, it has limitations which the reader should note:

- **missed TUO initiatives** - conducted over a relatively short period of time, the review will undoubtedly not have identified or included TUO initiatives that readers will be aware of. We apologise for these omissions and ask that information about any missing examples are sent to [christopher.fitch@bristol.ac.uk](mailto:christopher.fitch@bristol.ac.uk)
- **UK only focus** - similarly, international examples of TUO were not covered by the review (including the innovative Australian 'One Stop, One Story' model based on data-sharing between multiple essential service sectors - see Figure 7). We hope to address these international examples in a later review update.
- **lived experience** - our review team included individuals who specialise in data-sharing and TUO systems, and who also have experience of disability or vulnerable situations. However, this is not the same as undertaking research with a representative sample of people with lived experience about their perspectives, engagement, and evaluation of TUO systems. We aim to secure funding to undertake such research in the future.
- **physical TUO approaches** - by including physical media (such as cards, lanyards, booklets) and digital approaches in our review, some readers may feel we have stretched the concept of TUO too far. We accept this critique so far that differences do exist between, for example, a written booklet or form that can be physically shared with multiple organisations, and an online platform distributing person data across sectors. However, given that many of the online platforms in our review were lacking non-digital channels of engagement, important lessons can be drawn from physical TUO approaches in terms of creating hybrid digital and physical models.

### **Figure 7: One Stop, One Story (OSOS) Hub - Australia<sup>27</sup>**

OSOS allows people in crisis to share their circumstances once and gain access to support from multiple essential services. It was created by the Thriving Communities Partnership.

Launched in 2021, the system is unique because it is a referral platform used by frontline workers. When a customer speaks to a trained staff member at a participating bank or community centre, that worker can use the Hub to send a secure referral to other essential service providers the customer needs help from.

Major partners include Telstra (telecoms), Commonwealth Bank, AGL (energy), and several water firms. Critically, OSOS shows that TUC does not need to be a single national database. Instead, it can be a secure, collaborative network where different sectors - utilities, finance, and community support - work together to wrap support around the person.

To date, the OSOS Hub has recorded over 7,000 referrals between 20+ partner organisations, with data showing that 87% of the people referred had not reached out for help before.

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# Appendix 1: Biographies/Interest statements

**Dr Christopher Fitch** is Vulnerability Lead at the Money Advice Trust, a Research Fellow at the Personal Finance Research Centre (University of Bristol), and a Fellow of the Royal Society for Public Health. Since 2007, he has led a programme of guidance, research, training, and intervention on vulnerability across the essential services sectors.

**Register of interest:** Chris advises the Experian Support Hub project in a paid capacity.

**Ben Bennetts** is Policy Impact Manager with Impera Analytics. He has spent his career in local government, and now works with the public sector and other organisations to improve the way they record, manage and use data, with a particular focus on helping people from marginalised communities get the services and support they need.

**Register of interest:** None.

**Dan Holloway** is Co-convenor of the Futures Thinking Network at The Oxford Research Centre for the Humanities, and researches and writes about disability, technology, and inclusion. He is CEO of the University of Oxford spinout Rogue Interrobang. Dan has lived experience of bipolar disorder and a selection of neurodivergences.

**Register of interest:** Dan advises the Experian Support Hub project in a paid capacity.

**David Atkins** has over 30 years' experience in financial services, specialising in risk management, audit and inclusion. As Head of Group Customer Vulnerability at a large UK Retail bank, he led strategies to improve outcomes vulnerable customers. He is now a Trustee and Deputy Chair of a mental health charity, and works with the Money Advice Trust as a vulnerability consultant.

**Register of interest:** None.

**Faith Reynolds** works in an advisory capacity across a range of inclusive finance and fintech initiatives. She has been a leader in developing Open Banking and Smart Data in the UK, and is a strategic advisor at Electralink, The Connection Project and The Investing & Savings Alliance.

**Register of interest:** Faith is a member of Project Nemo, a non-executive director at Nest Corporation and Chair of the Advisory Board for UKFin+.

**Johnny Timpson OBE** has lived experience of disability and is a Financial Inclusion Commissioner and a member of both the Building Resilient Households Group and GAIN (the Group for Autism, Insurance, Investment and Neurodiversity) and has disability and legal services charity trustee roles.

**Register of interest:** Johnny holds roles with the Surviving Economic Abuse, Caudwell Children and LegaCare Charities; Vocational Rehabilitation Association UK; Financial Services Consumer Panel; the National Independent Consumer Organisation; Age Irrelevance; International Longevity Centre; We Thrive CIC; Calling All Minds and is Non-Executive Chair of Morgan Ash (a vulnerability tech firm) and Absolute Military (armed forces and veterans financial inclusion and capability specialist firm).

**Kevin Still** is a director of trade body DEMSA, a NED for the Vulnerability Registration Service (VRS), sits on the MaPS SFS governance group and part of the HM Treasury Fairness Group, including the innovation and ability to pay sub-groups.

**Register of interest:** these roles are undertaken on a voluntary and unpaid basis.

**Lee Healey** is the founder and CEO of IncomeMax, a social enterprise helping families in the UK to maximise their income and take control of their finances. Lee is also an advisory board member for the Money and Mental Health charity, a MALG ambassador, and a stakeholder representative for the Energy UK Vulnerability Commitment Advisory Board.

**Register of interest:** IncomeMax is funded through partnerships where there is a specific interest in supporting vulnerable people.

**Liz Brandt** is Cofounder and CEO of Ctrl-Shift and has a career that has focused on the opportunities created where people, business and technology meets. Over the past 20 years, she has focused on the opportunities that the sustainable use of personal data brings for businesses, individuals, and society, and has worked extensively with Blue Chip businesses, Governments and Legislators and Think Tanks to support the development of our personal data economy.

**Register of interest:** nil

**Steve Crabb** is an independent chair and non-executive director specialising in improving the experience of customers in the utility sector in general, and those with additional service needs in particular.

**Register of interest:** Steve has previously advised the Experian Support Hub project in a paid capacity, and has also previously been paid for advice for PSR data sharing by water industry body Water UK.

## External assistance

This study was not undertaken with external grant funding and was instead supported ‘in kind’ by the Money Advice Trust, University of Bristol, and WhatWeNeed.Support.

The study team received a gift voucher for £18 from the Sunflower team in order to purchase a Sunflower Extra card to inform our review of their services.

The report design was undertaken pro-bono by the Experian in-house design team (and we are very grateful to the team for doing this).

# Appendix 2: Definitions

## Disability

### Social model (Scope, 2024)

"[P]eople are disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets. Or they can be caused by people's attitudes to difference, like assuming disabled people can't do certain things."<sup>28</sup>

### Equality Act (2010)

"A mental or physical impairment...[with] a substantial and long-term adverse effect on a person's ability to carry out normal daily activities"<sup>29</sup>

## Vulnerability:

### FINANCIAL CONDUCT AUTHORITY

"A vulnerable customer is someone who, due to their personal circumstances, is especially susceptible to harm, particularly when a firm is not acting with appropriate levels of care"<sup>30</sup>

### OFGEM

"[A consumer is vulnerable] when [their] personal circumstances and characteristics combine with aspects of the [energy] market to create situations where [they] are: significantly less able than a typical consumer to protect or represent [their] interests; significantly more likely than a [domestic] consumer to suffer detriment or that detriment is likely to be more substantial"<sup>31</sup>

### OFCOM

"Anybody can face circumstances that lead to them becoming vulnerable - temporarily or permanently. This might include physical or mental health problems, specific characteristics such as age or literacy skills, or changes in personal circumstances such as bereavement, job loss or changes in household income. [We] refer to people whose circumstances have led them to becoming vulnerable as 'vulnerable customers'. We recognise that organisations use a range of different terminology and some people might not like to be labelled as a vulnerable customer"<sup>32</sup>

### OFWAT

"A customer who due to personal characteristics, their overall life situation or due to broader market and economic factors, is not having reasonable opportunity to access and receive an inclusive service which may have a detrimental impact on their health, wellbeing or finances"<sup>33</sup>

## ICO

“Individuals can be vulnerable where circumstances may restrict their ability to freely consent or object to the processing of their personal data, or to understand its implications... Most obviously, children are regarded as vulnerable to the processing of their personal data since they may be less able to understand how their data is being used, anticipate how this might affect them, and protect themselves against any unwanted consequences. This can also be true of other vulnerable sections of the population such as elderly people, or those with certain disabilities. Even if the individuals are not part of a group you might automatically consider vulnerable, an imbalance of power in their relationship with you can cause vulnerability for data protection purposes if they believe that they will be disadvantaged if the processing doesn't go ahead.”<sup>34</sup>

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