DHI's Co-Design Activities for a Future Digital Passport for People with Profound and Multiple Learning Disabilities

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This is a final report though if you have any feedback then please contact the authors.

1 Introduction

The Digital Health & Care Innovation Centre are working with the Fraser of Allander Institute, SCLD (Scottish Commission for People with Learning Disabilities) and PAMIS on a short project to better understand how the PAMIS digital passport could integrate with cornerstone NHS and social care electronic records in the near future. Particularly, we are focussing on potential integration with the National Digital Platform (NDP) currently being developed by NHS Education for Scotland (NES). The NDP represents the near future of record keeping in Scotland. The DHI took a participatory design approach by supporting a group of pertinent, professional participants (including some people with lived experience from the SCLD Digital Navigator Board[1]) to co-design a viable and preferable future version of the PAMIS Digital Passport. We are following a participatory design approach where we will gather and support the design ideas and expertise of experts in this area.

The exploratory work took place over two participatory design workshops led by the DHI on the 28th January 2025 (attended by 16 participants) and 20th February 2025 (attended by 16 participants with high overlap from the first workshop). An extra three participants were interviewed on the 24th February 2025. Participatory design is a process where the participants, in this case experts in service delivery for people with profound and multiple learning disabilities (PMLD), who own and know most about the problems they face, are supported by professional design researchers, to co-design a future innovative service, system or product that is preferable to themselves.

Section 2 shows the learning from the participatory design workshops and the participants key design decisions. Key features are highlighted.

Section 3 shows further context from participants, again contributed at the workshops.

[1] https://www.scld.org.uk/what-we-do/digital-transformation/

Section 4 shows example of other apps, record keeping systems, etc. that are doing similar work or highlight similar features as are recommended here. The **HearMeNow** app (mentioned in Section 4, point 4) is particularly noteworthy for its features that overlap with some of the findings in Section 2.

Section 5 shows all the requirements for the future Digital Passport in one list and each requirement is also included in context of the findings from the workshops, and *highlighted*.

Section 6 notes some possible follow-on research activities.

Section 9 shows the screens of a prototype produced by the DHI to illustrate how the future Digital Passport might work.

1.1 Three options for implementing the Future Digital Passport

Note that only option 3 is viable for improving the digital integration of a future Digital Passport. The other two options exist to highlight alternative futures.

1. Upload the existing PAMIS Digital Passport to the NDP (or a similar thing remade outside of Microsoft PowerPoint – just moving out of PowerPoint, in itself, would make integration more possible – as described in Section 2.6). This keeps self-expression, and upholds the points in Section 2.8.
2. Use a 'structured data' model (e.g., DHI's Community Connections platform) despite the fact that it reduces the expressive abilities of the PAMIS Digital Passport. This would fit the desire to have a solution for all in Scotland, that drives automation and personalisation and not a separate digital record service for people with PMLD.
3. Use a hybrid method, based on the structured data focus e.g., DHI's Community Connections model but with significant changes to allow expressive, self-description, multi-media and integration with the NDP - people with PMLD will use these records in the way they want to and this may be different from what the NDP are looking to support. Inclusive design often benefits all people.

2 A Proposal for a Future, Preferable Digital Passport that would Integrate well with the National Digital Platform and wider systems

Here we present a design for a future vision of a Digital Passport for people with profound and multiple learning disabilities. This Digital Passport is based on the current PAMIS Digital Passport but we will refer to it here as a future 'Digital Passport.' All background IP stays with the project partners and funders and is not affected by this proposal. Foreground IP generated during this project is owned by the funders (Fraser of Allander). DHI will publish the knowledge, for example, in a research journal. Ideally, this future Digital Passport will support some level of integration with the National Digital Platform (NDP) currently being developed by NES[2]. The NDP will be a single source of medical (NHS) and care service (local authority) data about a person. Inevitably, it will not cover all aspects of a person's health and care and so other storage solutions and applications will have to co-exist and interoperate with it. The future Digital Passport could be of use outside of the NDP as discussed in

[2] https://www.nationaldigitalplatform.scot/

Section 2.4: The Wider Context of Data. The NDP is closely aligned with Scotland's Digital Front Door plans[3] and the wider integration of health and social care records[4].

Note there will be future decisions to be made about the operating model for these kinds of person-held records. These relate to branding/product features and the balance between organisation or special group delivery methods, versus creating generic, reusable functionality at a 'once for Scotland' level for multiple groups and organisations.

For example, in the future there may be a separate digital app, made by PAMIS or a software developer they partner with, that is branded PAMIS, integrates with some of the National Digital Platform and delivers a very specific user experience. Alternatively, there could be a reusable National Digital Platform module called something like 'My Voice', 'My Story' or similar, branded as part of the national infrastructure, which provides some flexibility for multiple groups and organisations to configure different experiences as required.

This paper does not recommend an operating model, but understanding these possible directions will help people consider some of the principles and developments needed to underpin either/both models.

Four existing sources were considered when designing a future Digital Passport as shown in Figure 1. These were the existing PAMIS Digital Passport; model suggestions from Workshop 1 of this project; Professional Record Standards Body (PRSB)'s About Me model; and the DHI's Community Connections web-app that comes from the DHI's Moray Growth Deal funded Rural Centre of Excellence work (and is a structured data version of PRSB's About Me model).

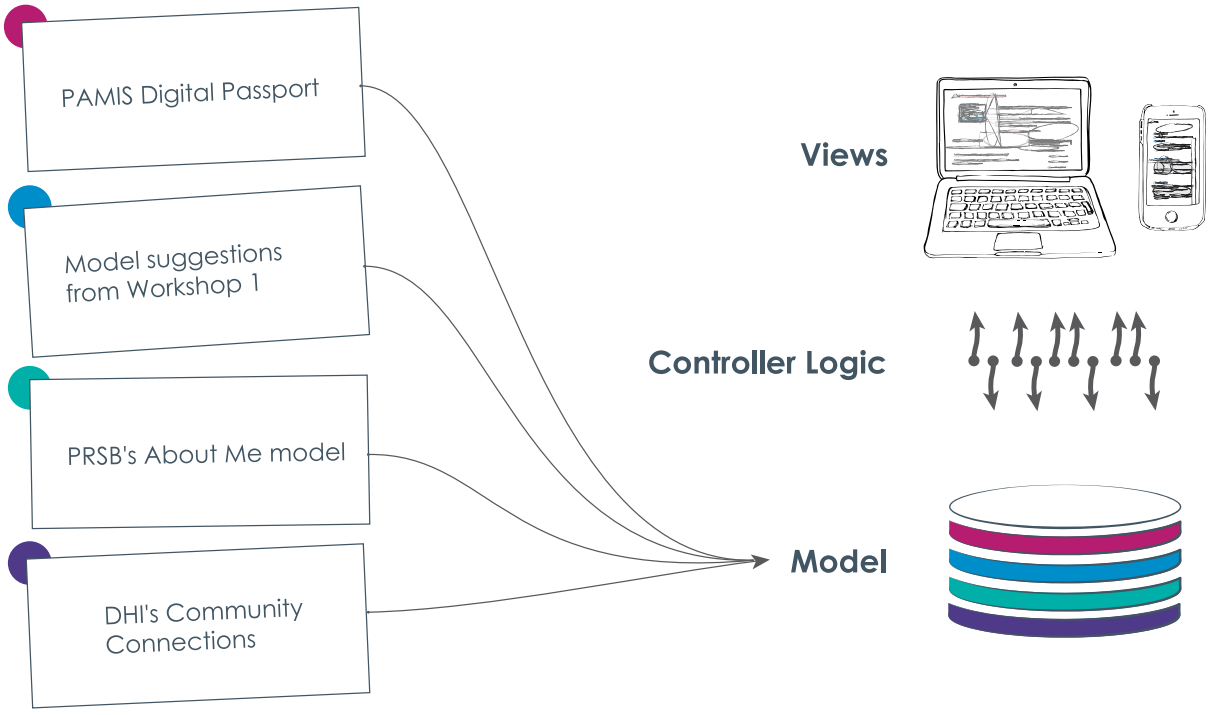

Figure 1: Sources of data considered for a future Digital Passport model. Possibe future views are shown in Section 9. This is the model-view-controller paradigm. The model-view-controller paradigm is explained in Section 2.1.

[3] https://www.digihealthcare.scot/our-work/digital-front-door/
[4] https://www.gov.scot/publications/data-strategy-health-social-care-2024-update-progress-priorities/

2.1 Model-view-controller

It is helpful to consider any record as three components as on the righthand side of Figure 1. These are the:

Model: the data itself. There will be a description of the data fields. e.g., there is a forename field and it is a string of text. Data sharing rules would also be kept in the model (e.g., my care team can see this sub-set of data.);

Views: many organisations or individuals could potentially have a view of the same model that suits them. A viewer need not view, or have permission to view, all of the data. i.e., there is granularity and only some of the data may be included in a view.

Controllers: many organisations or individuals could potentially have permission to edit the data. Again, permission could be granular. Controllers can only do four possible things to the data (referred to as CRUD): **C**reate new data; **R**ead existing data; **U**pdate existing data; or **D**elete existing data.

A model need not be exhaustive. A model may focus on a particular aspect and another model can be relied on to provide other data outside the scope of this model. i.e., models can be aggregated for the purposes of views or controllers. There may be a more or less significant overlap with other data models that will be in the National Digital Platform. Where possible, data should not be duplicated. For example, if we have controller permissions and we wish to store a person's forename, and the NDP already provides that field, then we should use the NDP's forename field.

2.2 Overlapping Data

There is a spectrum of overlapping data between a future Digital Passport and the NDP (and other sources of data). Two possibilities are shown in Figure 3 (low overlap) and Figure 2 (high overlap). Overlapping data means that the data does not need to be replicated. We do not know what will be in the NDP but can assume that it will include most or all data from statutory health and care services. We might assume that it will focus on health and care delivery data as opposed to a person's own narrative of their health and care (as it is owned and initiated by NHS Scotland).

The digital passport content extends beyond learning disabilities and other health conditions.

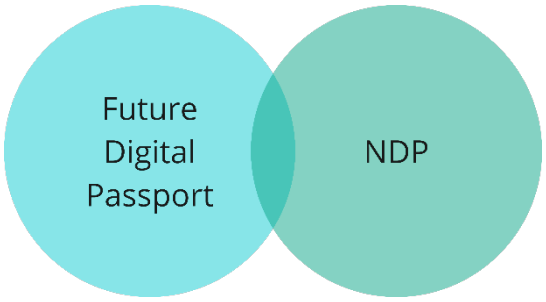

Figure 2: A future where there is little overlapping data between the Digital Passport and the NDP.

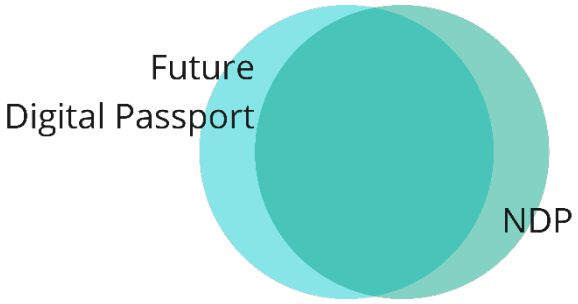

Figure 3: A future where there is a lot of common data in the Digital Passport and the NDP.

2.3 Person-owned Records or Personal-data Stores

Person-owned records (or personal data stores) can be used by individuals to store any data they might want to. The data is sometimes stored on their own device or sometimes stored online. They have control over the data - i.e., the CRUD abilities as above. The person can choose who to share sub-sets of the data with and what control that person would have over the data. Person-owned records are a suitable way for a person to self-manage their information and act as the 'point of integration'[5] for several services they use. The use of person-owned records is not commonplace in health and care services at the moment but the concept is becoming more prevalent. The DHI's Community Connections web-site provides people with a person-owned record and is (at the time of writing) being used in a limited test in Moray.

2.4 The Wider Context of Data

2.4.1 Everyday Life

The proposed future Digital Passport is not necessarily confined to being a health and care digital passport. As the person owns their information (in their personal data store), they are free to share it with anybody and any organisation. This could be informal carers, friends, etc. and organisations such as schools. Although the DHI's work on Community Connections and personal data stores is focussed on health and care innovation, the data store need not be solely focussed on health or care services. The proposed future Digital Passport here would use a personal-data store just like the DHI's work on Community Connections.

The HearMeNow app as mentioned elsewhere here, and specifically in Requirement 6, allows other people and organisations to send the person an invite for sub-sets of data. E.g., PAMIS could send the person an invitation to fill out a PAMIS Digital Passport. In this example, the PAMIS Digital Passport would be a set of fields to fill in and guidance. The person would use existing data when filling in such an invite. The person could then choose (or not) to share that data onwards. The proposed future Digital Passport can share into and out of many contexts. Data-integration is not guaranteed in any organisation though. That is, a receiving organisation may not be able to consume and use the shared data as part of their day-to-day activities. Much of the DHI's activity is working with organisations to change practice to use this kind of data.

2.4.2 Research

Personal data stores are useful for gathering research data (quantitative and qualitative). The person can be sent a request to fill in a sub-set of information. If they consent to be part of the research then they can share that data with the research organisation. This ability may prove useful when, for example, adding to the evidence base for challenges for people living with PMLD.

2.5 The PRSB About Me Model

"About Me is for any person (or their carer/guardian where the person doesn't have capacity) to share the things that are most important to them with the professionals and carers providing their care. It is intended to be generic and apply to everyone, from those who have complex care and

[5] https://mydex.org/resources/papers/Unlocking_the_value_of_our_paper/unlocking_the_value_of_our_data_-_mydex_cic.pdf

support needs to those who rarely require care and/or support. It is not intended for repeating information which should be in a person's record." [https://theprsb.org/standards/aboutme/]

Note that the PRSB say that some information should be in other records. i.e., the PRSB About Me model is not exhaustive of all data. We will adopt this approach with the Future Digital Passport proposed here. There are other PRSB models that cover more structured data.

Note that the PRSB About Me model is almost all free text (except one date field).

2.6 Structured and Unstructured Data

The participants asked that all fields should allow video, audio, image and free text options. This would allow maximum flexibility, inclusion and expression.

Participants agreed that text is more open to interpretation errors whereas video would be clearer in many cases, e.g., 'this is how I (or the person being cared for) expresses pain.'

Requirement 3: All fields should have text, video and audio options. This makes the form inclusive and expressive.

The inclusion of video and a means of communicating that video alongside structured data into a health and care organisation may support the use-case of using video for reasonable adjustments as currently being investigated for the PAMIS Digital Passport. Possibly this could align with the TEACH framework[6].

Structured data refers to a set of named fields (e.g., forename, date of birth) and their types (e.g., text, date) that can be read and processed by both humans and computers. The date of an upcoming appointment can be understood by a human reading it on a screen. It can also be read by a computer and an automated task triggered, for example, one week beforehand. Structured data supports automation, statistical analysis, automated auditing, etc. Structured data can sometimes restrict expression. I.e., if what you want to say does not fit anywhere on a form. Unstructured data, for example some text or a video, is more difficult for a computer to process but allows us much more freedom to express what we want to express. Video, images, audio and free text are all forms of unstructured data. Data in a PAMIS Digital Passport would be considered unstructured.

There is an obvious tension between free text as in the PRSB About Me model and structured information needed for integration, automation and automated personalisation (with the NDP or any other similar infrastructure). This applies for video, images and audio (see Figure 4).

6 https://assets.publishing.service.gov.uk/media/5a82ad44ed915d74e340300b/Social_care_staff_supporting_reasonable_adjustments_in_learning_disabilities.pdf

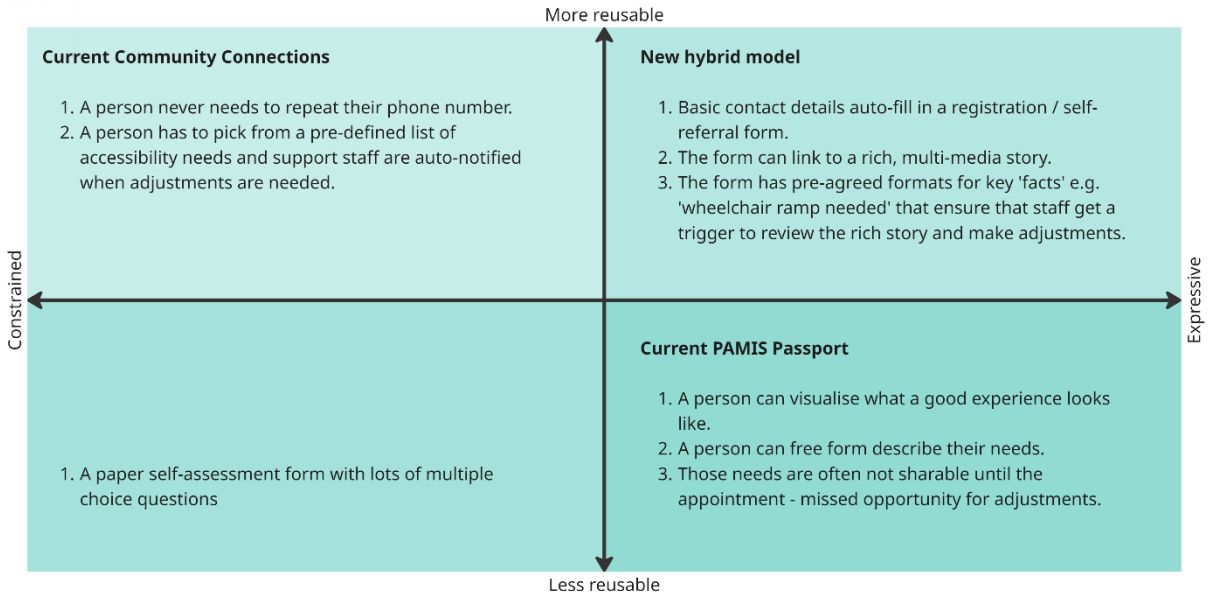

Figure 4: Spectrum of freedom to express through to structured data. Of course, structured data can also be expressive.

Priorities will be (potentially very) different from person-to-person. The PAMIS Digital Passport supports that difference. Can the NDP do the same? It would be interesting to compare and contrast the two approaches (sets of data) for the same person in future work.

Requirement 1: People should be able to skip sections that aren't relevant. Or, never be shown them in the first place based on earlier questions. This second part will need further work to determine what is and isn't suitable to show and what questions should trigger the changes.

2.7 Requirements for Digital Information Storage and Sharing

1. Sharing video and images with staff in new services helps to humanise the person. This challenges/corrects the 'sub-human' narrative and stereotypes. It challenges assumptions of professionals who may have difficulties in working with e.g., people with communication challenges or are non-verbal. For example, sharing video of the person in a family setting can change perspective of professionals. This applies for all people who could be classified as different. The person's voice is paramount. e.g., need to avoid professionals talking to carers rather than the person themselves.

Requirement 3: All fields should have text, video and audio options. This makes the form inclusive and expressive.

2. Information should be timestamped and include the author to aid people to assess how up-to-date it is. e.g., Advanced Care Planning and other care plans. Previous entries should be kept as history for each field. Authors are important when delegated access is considered. The person may enter their own data with their own log-in and identity. However, the person may delegate access to others (e.g., a family or informal carer) and it is important to know who has entered the information. Delegated access is not included in the DHI's Community Connections and it remains an open research question.

Requirement 4: All data-entry should be time-stamped, include the author and previous entries kept in a history. This overlaps with the issue of delegated access.

Requirement 8: Timeline view of data entered/changed/deleted.

3. Many people with PMLD would use services in multiple healthboards.

Requirement 5: The future Digital Passport must be a 'once for Scotland' system. i.e., avoid ownership by any territorial healthboard. That is, the provision of the future Digital Passport must not be owned by any one healthboard.

4. Some professionals are granted permission by people and their carers to edit their PAMIS Digital Passport directly.

Requirement 6: Sub-sets of the data should be shareable as editable or read-only. This should be electronic (formal, i.e., shared with NDP and, informal, i.e., 'let me neighbour see this section') and paper. The stories as imagined in Section 9 should be shareable. This is similar to the feature in the HearMeNow app. The HearMeNow app is a good model to learn from and there may be opportunities to work with them in future.

5. There may be much more information than the NDP would want to store. What would a hybrid storage solution look like? Could we store pointers into a future PAMIS Digital Passport? Or have some data in the NDP and some in a future PAMIS Digital Passport?

6. Emergency section of Digital Passport needs to be relevant for the Emergency Department where time may not be spent on full details about the person but still must respect their immediate needs attendance (PAMIS has already done some work on preparing necessary Emergency Department information). In the proposed Digital Passport, a story could be created for emergency situations. This story would presumably be labelled, 'In case of emergency', or similar.

Requirement 2: People should be free to express their health story as they wish or need to. People must be able to build their own narrative and determine what is and is not important to see and in what order. This should ideally still allow as much structured data as possible. This is what the prototype screens in Section 7 labels as 'stories.'

2.8 Self-description

1. The Digital Passport must aim to be engaging and support description of how the person wants to describe themselves or the person they care for.

2. Taking a person-centred approach would get 'more out of the person' in terms of what's important to them.

3. The digital passport is more accessible and interactive. Would a standardised form like what the NDP might be, reduce engagement and the returned information?

    a. Format would be more standardised. However, this standardisation may put people off.

    b. Self-representation (in and of itself) is beneficial. This is taken away by standardised forms.

4. For now, it is assumed that the proposed future Digital Passport is owned entirely by the person and the person can grant access to their carer or anyone else they wish to have access. A PAMIS digital passport currently might tell the story of the person and their carer. This is not usually the clinical focus within the NHS and presumably would not be the focus of the NDP. There remain some open questions to be discussed in future. Is there any place for joint records in the future? What if we have a health story that is owned by two or more people? There must be exemplars in, for example, maternity record keeping.

2.9 Information Prioritisation

1. Communicating the pertinent information at the right time. That is, there should be feature allowing users to add a priority (order) for the information. This is the order of information is either set by the person for everyone who it is shared with or, the order could be set by the person but also determined by who is viewing it.

    a. Some information is important at first. i.e., getting people through the door. Knowledge of this information is important.

    b. Emergency button on front page, or similar. i.e., if in emergency situation a clinical professional could see important clinical information. Could be used for different contexts, e.g., pharmacy, etc. Key information for each context. i.e., KIS[7] integration?

    Requirement 9: People should be able to set the 'context of use' (e.g., emergency scenario) and then get prompts around what that context might need and what professionals are going to ask for as a priority to them (e.g., paramedics asking about an allergy before administering treatment). This will allow citizens to build stories that are more easily acted on by support teams.

    c. e.g., NHS Forth Valley. Paper records. Emergency (need to know) have red borders

    d. Summary i.e., 'two sides of A4'. Maybe 4-5 sides is more realistic. Restricted space on paper leads to concise descriptions.

    e. Would a planned admission/unplanned admission with acute information and non-acute information perhaps meet the purpose of emergency staff needing a certain type of information vs. the type of information needed during planned admission and discharge?

    f. Possibly a 'critical path' of what must be seen first by professionals. e.g., communication might be high priority. Person-centred approach means person themselves or near carer should be able to set a 'critical path' or order of what must be seen. Priority might change given context. e.g., emergency department. The 'three things' resource developed by The Assembly fits with this approach[8]. The context may change in many ways. We often assume a human is eyeballing a screen with a visualisation of the Digital Passport and so priority relates to the order on the page. The priority is going to need to be negotiated between citizens and systems. Otherwise, the citizen's record may be ignored by professionals who are constrained by practice, processes or systems that require them to act in certain ways. For example, during the COVID-19 pandemic the first question upon entering a clinical setting would be 'are you vaccinated/had a recent

[7] https://www.scimp.scot.nhs.uk/key-information-summary
[8] https://www.theassembly.scot

covid test?' No amount of self-expression would have been tolerated before that answer is given because of the imperative to keep staff and other patients safe.

g. We also need to consider how software systems are fed data. So, the context could be appointment booking online. Now the need for a wheelchair ramp (structured data from a multi-select about access needs) is a high priority piece of information, otherwise the person could be booked into an inaccessible building and the appointment fails.

As above, this requirement is listed again here: 1 People should be able to skip sections that aren't relevant. Or, never be shown them in the first place based on earlier questions. This second part will need further work to determine what is and isn't suitable to show and what questions should trigger the changes.

People should be free to express their health story as they wish or need to. People must be able to build their own narrative and determine what is and is not important to see and in what order. This should ideally still allow as much structured data as possible. This is what the prototype screens in Section 7 labels as 'stories.'

2. Is it possible to have a long and a short version - for each field? What you need to know and then underlying information.

3. Search bar - Add search bar to lookup info.

Requirement 7: There should be a search facility.

4. Timeline view. 'If someone had told me to keep a timeline of my daughter's medical care from birth, this would have saved me and many, many doctors a great deal of time.' – Participant at workshop.

Requirement 8: Timeline view of data entered/changed/deleted.

2.10 Information (possibly) not covered by the PRSB About Me model

1. There is no obvious location in the PRSB About Me model for information such as:

    a. 'What is life to me' or,

    b. 'What I am doing and what support I want to live my life that way'.

    c. How I show when I'm in pain and how I show when I'm unwell.

3 Context

One particularly pertinent context for testing or future use of the future Digital Passport would be the, 'Scottish Annual Health Check for People who have a Learning Disability'. This model should support this context. This normally happens in a physical space/room. See https://www.gov.scot/groups/adult-learning-disabilities---annual-health-checks-national-implementation-group/, https://learn.nes.nhs.scot/63167 and https://www.gov.scot/publications/scottish-annual-health-checks-for-people-16-with-learning-disabilities for more context. Note that the proposed Digital Passport is designed to integrate well with the NDP (which represents the near-future best practice in Scotland) and align with the most

prevalent ‘once for Scotland’ planning, but it could be used to support a stand-alone activity such as the Scottish Annual Health Check for People who have a Learning Disability without any integration with NHS or care service infrastructure.

3.1 Digital Information Storage and Sharing

1. The Digital Passport may be the only way that the person's voice can be heard in some contexts.
2. Data shared should ensure the person is included in any decisions.
3. Avoiding repetition is extremely important where people may find communication challenging and/or very time consuming. Note that this links to earlier points in Section 2.9, 1.f. Repetition is usually required because organisational systems demand fixed answers to fixed questions. Do you have a covid-vaccine (yes/no)? What is your formal diagnosis (multi-select/drop-down)? If the data entered is unstructured (e.g., free text), then there is little prospect of those fixed data requirements in organisational processes being met, which means the staff will ask the questions again to get answers. This will repeat in every team, tier and service. So, we will need to accompany unstructured data with as much structured data as possible if repetition removal is needed.
4. Early questions in the first workshop included
    a. Who owns the data?
        i. When in the PAMIS Digital Passport?
        ii. When in the NDP?
    b. Our proposal, here, is that in the proposed new Digital Passport the person would own the data (i.e., held in a personal data-store) and put data sharing agreements in place for e.g., family, carers, NHS boards, councils, etc.
5. Sharing a future PAMIS Digital Passport should help make sure that the requirements of the Adults with Incapacity Act are met.

During the first workshop, participants were asked to consider how the PAMIS Digital Passport does and does not work well and these are shown here to improve understanding of the context of use (Section 3.2 and 3.3).

3.2 Things participants thought work well about the PAMIS Digital Passport and information sharing (e.g., considering the specific transition process from child to adult)

1. Images and video help bring the individual into the centre of transition to new services and help to humanise the person.
2. Can make sure that the legal requirements to make reasonable adjustments are met.
3. Digital Passport helps to plan discharge. Reducing bed blocks.

4. Person or carer shares video with care team who lack English as a first language. This helps to communicate needs without large amounts of text.
5. Digital Passport is shared as an education tool for staff. Staff may never have worked with person or similar needs. Being tailored to the individual.
6. Digital Passport is shared to new (adult) services that are not familiar with the person and/or their needs.
7. All important information is in the Digital Passport. This reduces duplication and potential confusion.

3.3 Things participants thought do not work well about the PAMIS Digital Passport and information sharing (e.g., considering the specific transition process from child to adult)

1. Some clinical areas (not all) may not look at documents or tools that are not from within their own healthboard.
2. Some people and carers will lack technical skills and/or time to start a PAMIS Digital Passport.
3. Digital Passport is not shared early enough before accessing service. Staff do not have time to look at the contents. Often staff systems cannot prompt them to look at a specific need without the necessary integration and structured data to drive clinical workflow.
4. Information shared from the Digital Passport could then be stored and used by the receiving organisation. Could the information be retracted later?
5. Organisations may reject an alternative source of information and not engage or not be able to engage according to information governance.
6. Sometimes a hard copy is needed. How could people make a hard copy?
7. The shared information must go to the correct people, those who will be supporting the individual.

4 Existing Digital Information Storage and Sharing Solutions of Interest

1. NHS Tayside use FICare (Family Integrated Care) in neonatal to transform service delivery to involve carers and family. There are some overlaps with the PAMIS Digital Passport and DHI's work on Person-owned Data Stores.
2. "At Ninewells Hospital NICU we believe in Family Integrated Care. This means that we recognise that you, the baby's family, are the most important people in your baby's care."
   - https://www.nhstayside.scot.nhs.uk/OurServicesA-Z/NHSTCommunityChildYoungPeopleandFamilies/PROD_349574/index.htm
3. "Family Integrated Care (FICare) is a model of neonatal care promoting a culture of partnership between families and staff; enabling and empowering parents to become confident,

knowledgeable and independent primary caregivers" (BAPM, 2021)."
- https://perinatalnetwork.scot/neonatal/ficare/.

4. HearMeNow app has some similarities with what a future PAMIS Digital Passport could be like (https://www.hearmenowapp.com). It also implements the PRSB's About Me data model as in Section 2.3. HearMeNow features include: self-labelled data fields. Multimedia. Sharing via contacts. Requests from others (e.g., 'please fill in this form', 'please add this field to your record'). Also has calendar and appointments.

   This is an implementation of Requirement 6: Sub-sets of the data should be shareable as editable or read-only. This should be electronic (formal, i.e., shared with NDP and, informal, i.e., 'let me neighbour see this section') and paper. The stories as imagined in Section 9 should be shareable. This is similar to the feature in the HearMeNow app. The HearMeNow app is a good model to learn from and there may be opportunities to work with them in future.

5. ARC Scotland (https://arcscotland.org.uk/) would be a good stakeholder to speak to in future. They are a 'charity that advances knowledge, practice and policy in health and social care for the benefit of people with learning disabilities or other support needs such as autism, mental health problems, sensory and physical disabilities.'

6. vCreate Neuro '..., creating a secure, cloud-based web-app for patients and carers to share video and associated clinical data remotely. vCreate Neuro is a collaboration between Paediatric Neurology Services in NHSGGC and vCreate Ltd, supported by the West of Scotland Innovation Hub.' (https://www.vcreate.tv/neuro).

5 List of all Proposed Features

1. People should be able to skip sections that aren't relevant. Or, never be shown them in the first place based on earlier questions. This second part will need further work to determine what is and isn't suitable to show and what questions should trigger the changes.

2. People should be free to express their health story as they wish or need to. People must be able to build their own narrative and determine what is and is not important to see and in what order. This should ideally still allow as much structured data as possible. This is what the prototype screens in Section 9 labels as 'stories.'

3. All fields should have text, video and audio options. This makes the form inclusive and expressive.

4. All data-entry should be time-stamped, include the author and previous entries kept in a history. This overlaps with the issue of delegated access.

5. The future Digital Passport must be a 'once for Scotland' system. i.e., avoid ownership by any territorial healthboard. That is, the provision of the record must not be owned by any one board.

6. Sub-sets of the data should be shareable as editable or read-only. This should be electronic (formal, i.e., shared with NDP and, informal, i.e., 'let me neighbour see this section') and paper. The stories as imagined in Section 9 should be shareable. This is similar to the feature in the

HearMeNow app. The HearMeNow app is a good model to learn from and there may be opportunities to work with them in future.

7. There should be a search facility.
8. Timeline view of data entered/changed/deleted.
9. People should be able to set the 'context of use' (e.g., emergency scenario) and then get prompts around what that context might need and what professionals are going to ask for as a priority to them (e.g., paramedics asking about an allergy before administering treatment). This will allow citizens to build stories that are more easily acted on by support teams.

6 Testing and future work

It would be enlightening (suggested by participants) to compare and contrast an existing PAMIS Digital Passport and another version remade in:

1. The current version of DHI's Community Connections web-app running as part of DHI's Moray Growth Deal funded Rural Centre of Excellence programme. This would not be for sharing the contents but to report back on the experience? It would be interesting to have a carer or person living with PMLD and a healthcare professional assess the process and information quality.
2. This newly proposed future Digital Passport (if made to some level of usability in the near future).

PAMIS have had some valuable talks with Social Security Scotland just prior to lockdown with a focus on people who have profound learning disabilities (and their parents and carers) not having to continuously evidence an inability to work and evidence for benefits. There may be potential for some collaborative work in future. i.e., the future digital passport may be useful outside of the NDP integration context.

7 Possible Future Deployment Models

The project raised questions about what the scope of future digital passport work would be, who would be involved, who the audience is and what the scope of the solution would be.

This section outlines some ways of thinking about one or more future deployment models.

Option 1 – Status Quo

All partners agree a version of the report, publish it to share knowledge and enhance Scotland's understand of the 'art of the possible'. PAMIS, DHI and NDP all carry on as they are. Future project work may be possible when the time is right.

Option 2 – PAMIS Digital Passport Version 2 – Product Approach

PAMIS takes the specification and wireframes to a software developer looking to partner, finds some funding and makes a cloud-based version of the PAMIS Digital Passport, branded and owned by PAMIS, that can deliver some of the extended features proposed by this work. Said company could attempt to integrate the new passport with other platforms. DHI would offer continued advice and

facilitation if needed. DHI could joint bid for funding with others, and could help deliver a project to give PAMIS and others confidence.

Option 3 – Complex care "Module" on an existing digital platform

PAMIS and partners identify an existing platform that can be developed and configured to deliver digital passport capability. This would be a 'module' alongside other use cases on that platform (e.g., falls prevention, healthy living, etc.). The passport would not be called the 'PAMIS Digital Passport' but instead would be a 'complex care needs' focused module that many charities or organisations could use. PAMIS would get a sub brand/credit as the originators. PAMIS would share creative control with a network of users across different organisations in line with the existing platforms delivery model. DHI's Community Connections could be this platform.

Option 4 – Developing DHI platforms to offer more flexibility for all populations

DHI learns the lessons from the joint work and adapts its existing platforms to be more flexible and accessible for people with complex care needs, adding more multimedia, configurable interfaces and other features as in Section 5 to make what already exists better for a wide variety of groups with complex care needs. This would not attempt to deliver a discrete 'passport' and it would stay under an existing brand, e.g., Community Connections. PAMIS can continue to develop a specific PAMIS passport either in PowerPoint or as software, on their own or with assistance from the group as needed.

Option 5 – Lobbying the National Digital Platform / Digital Front Door team to create a flexible passport for all populations

The report is finessed with a view to campaigning for inclusion of these requirements in the pipeline for the National Digital Platform/Digital Front Door. There is already planned to be an 'About Me' section of the platform, with the National Care Service team pushing for the person's wishes to be at the heart of this section. PAMIS and partners would take the role of advocates and lobbyists to try and secure a seat at this table level of resource and adoption. DHI could support in this. The national platforms would decide the scope and be responsive to PAMIS and partners needs to a degree dependent on how well we collectively advocate/lobby. I.e., they may offer a relatively generic capability that ticks some boxes (flexibility, multimedia, etc.) but falls short of a 'passport' that the citizen feel control over. Or, they might be more adventurous and stay nearer to the proposed model, but this would take a significant change in outlook in the current scope of their work.

8 Suggested Future Work for Developing this Proposed Future Digital Passport

A roadmap would depend heavily on the options that PAMIS and partners prefer from the list above (or additional options not yet conceived). DHI would have no real position / priority or agenda and try to be responsive to the group's needs. Irrespective of the options selected, some next steps could be common in progressing our joint understanding and de-risking option selection:

1. The DHI could pursue funding to build more flexibility multi-media capability into their Community Connections web-site. The Community Connections web-site is currently funded by the Moray Growth Deal. The changes required would not be labelled as, 'for PMLD' but should be shared as a solution for anybody who would benefit from sharing their health

story. This would be a general 'good' for society, with DHI's existing work being positively impacted to be more inclusive because of this project. It could also lay the groundwork for an easier potential PAMIS specific development together in the future.

2. Participatory work with eHealth and information governance staff to review integration and related systems. This would help understand in more detail how appointment systems and other critical touchpoints could flag the presence of a digital passport in the future.
3. Further wireframe prototypes could be developed in a future project phase. An ideal candidate for this might be:
    a. Supporting a single approach across Scotland for the 'Scottish Annual Health Check for People who have a Learning Disability' as in Section 3. A version of the proposed Digital Passport could be developed to support an invitation to all relevant people and a dashboard for professionals to see the shared data (if shared by the person).
    b. As noted in Section 2.4.2, a version of the proposed Digital Passport could be developed to support data gathering for example, building the evidence base for challenges for people with PMLD. Addressing the suggested lack of data around e.g., digital exclusion, or gaps in transitioning from children's to adult services.

9 Prototype screens showing the proposed, future Digital Passport

These prototype screen can be opened in a web-bowers here:

https://www.figma.com/proto/ZrQqSzulQG6LN2gmyr6YkN/PMLD-Digital-Integration?node-id=1-432&t=c3tDT5A86nuRRZtr-1&starting-point-node-id=1%3A432&scaling=scale-down-width&content-scaling=fixed&disable-default-keyboard-nav=1&hide-ui=1

The prototype shows the following features from Section 5 that are key. Some features, such as the search bar, are well understood ideas and are not shown. Please note that the form builder for creating stories can be made a lot better in a number of ways. The prototype is illustrative of the new and interesting concepts but it should not be seen as the only, or best, way to implement the features.

The prototype illustrates the balance between allowing expressive data such as video, images, audio and free text and, structured data. In theory, someone using the future Digital Passport (as envisioned in the prototype) could avoid entering any structured data and could recreate the current PAMIS Digital Passport using video, image, audio and free text alone. The benefits of structured data would need to be communicated to the user. How to encourage an ideal balance between entering and reusing structured data and using unstructured data where needed is for future work. We might imagine many ways to facilitate an easy way for a person to tell a health story and have that story link to or re-use as much structured data as possible.

The prototype shows the concept of stories; a curated set of data that tells a particular story to someone else. These stories can be shared. These stories could be prompted, for example, an organisation like PAMIS could send an invite to the person, 'please follow these instructions and enter sufficient information to make a PAMIS Digital Passport.' Or, 'you have an appointment, please could you fill in a form for reasonable adjustments?' Stories do not have to be shared. Other DHI projects have shown that there is benefit to creating a story just for yourself. This can be useful in making sense of a potentially very large amount of information by connecting a range of events and details in a particular order.

Note that the label, ‘story’ may not be the most suitable word to describe the sub-sets of data. ‘Narrative’ or ‘report’ are similar words that could describe the same feature. ‘Form’ is presumably a pejorative term but also describes the sub-set of data adequately.

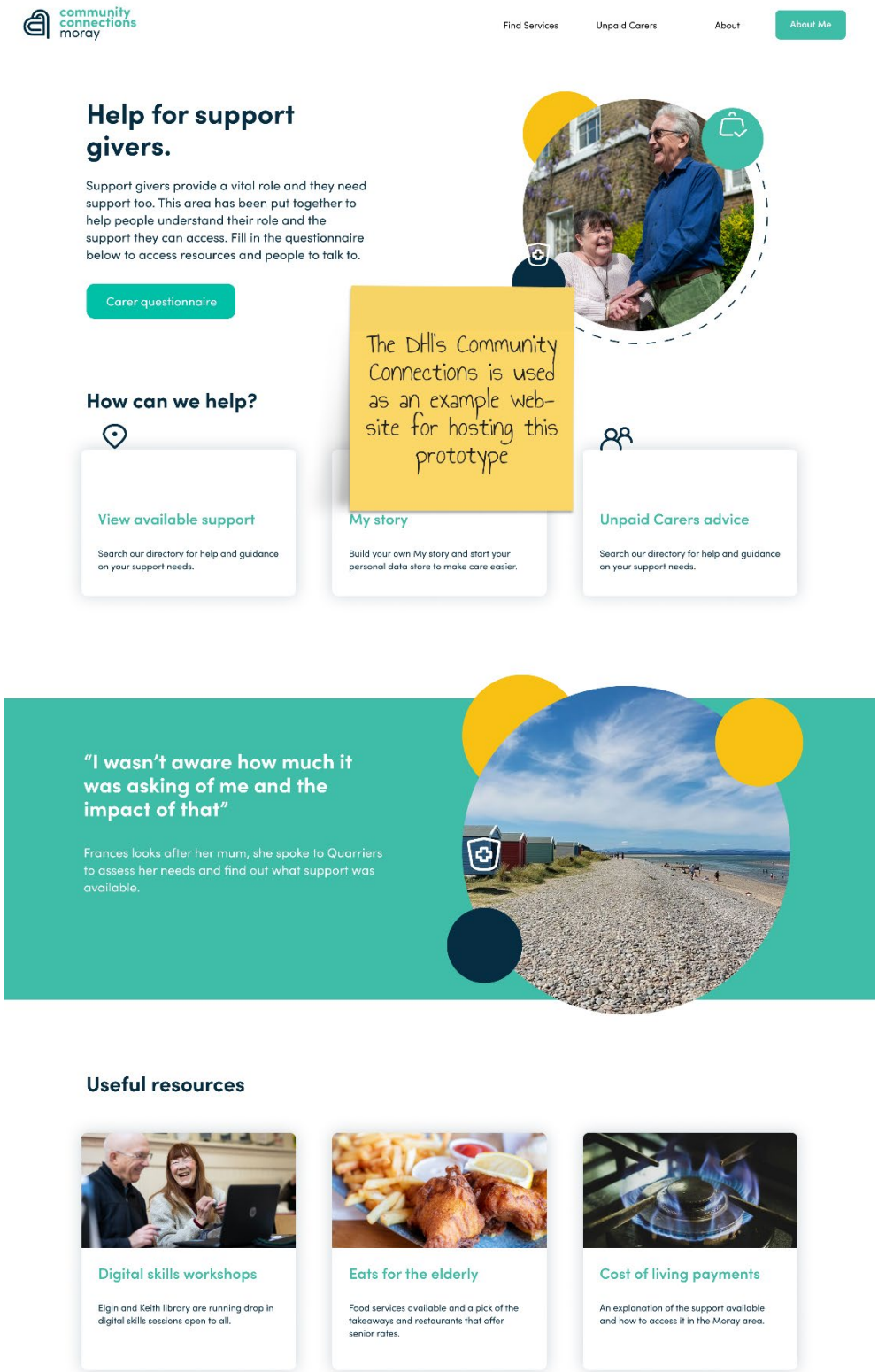

Figure 5: The landing page of the DHI's Community Connections. For this prototype, Community Connections could be the public accesible way to host the future Digital Passport.

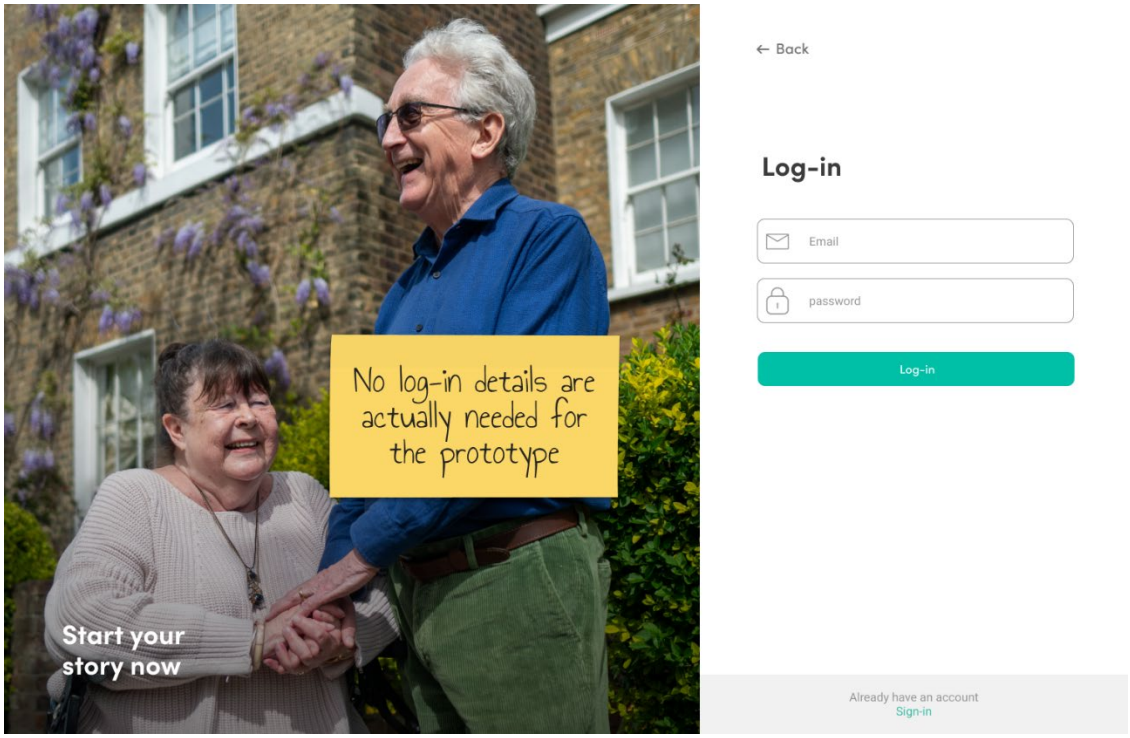

Figure 6: Each person has a log-in and the all data entered is stored in a person-owned record.

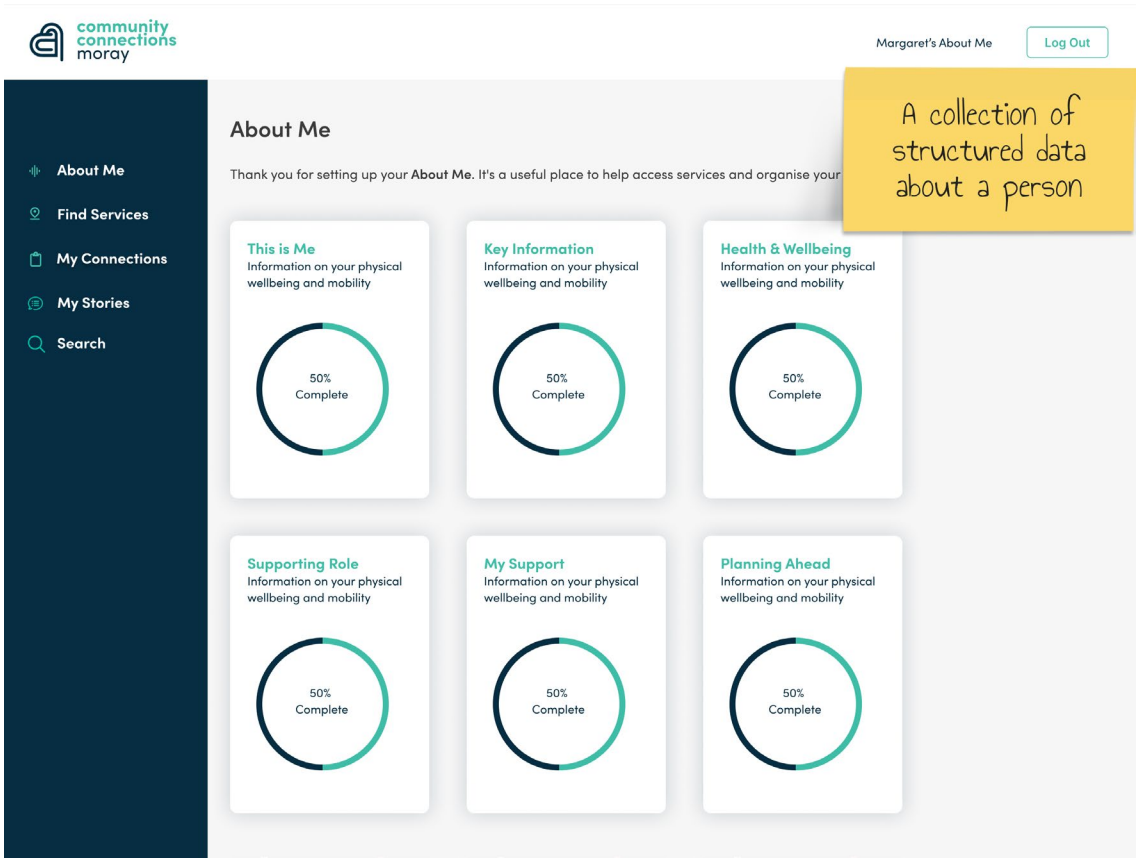

Figure 7: The main page of the Community Connections data store. Each category leads to further data fields. These categories and the data fields that they lead to are examples of structured data that is more easily integated with services such as the NDP.

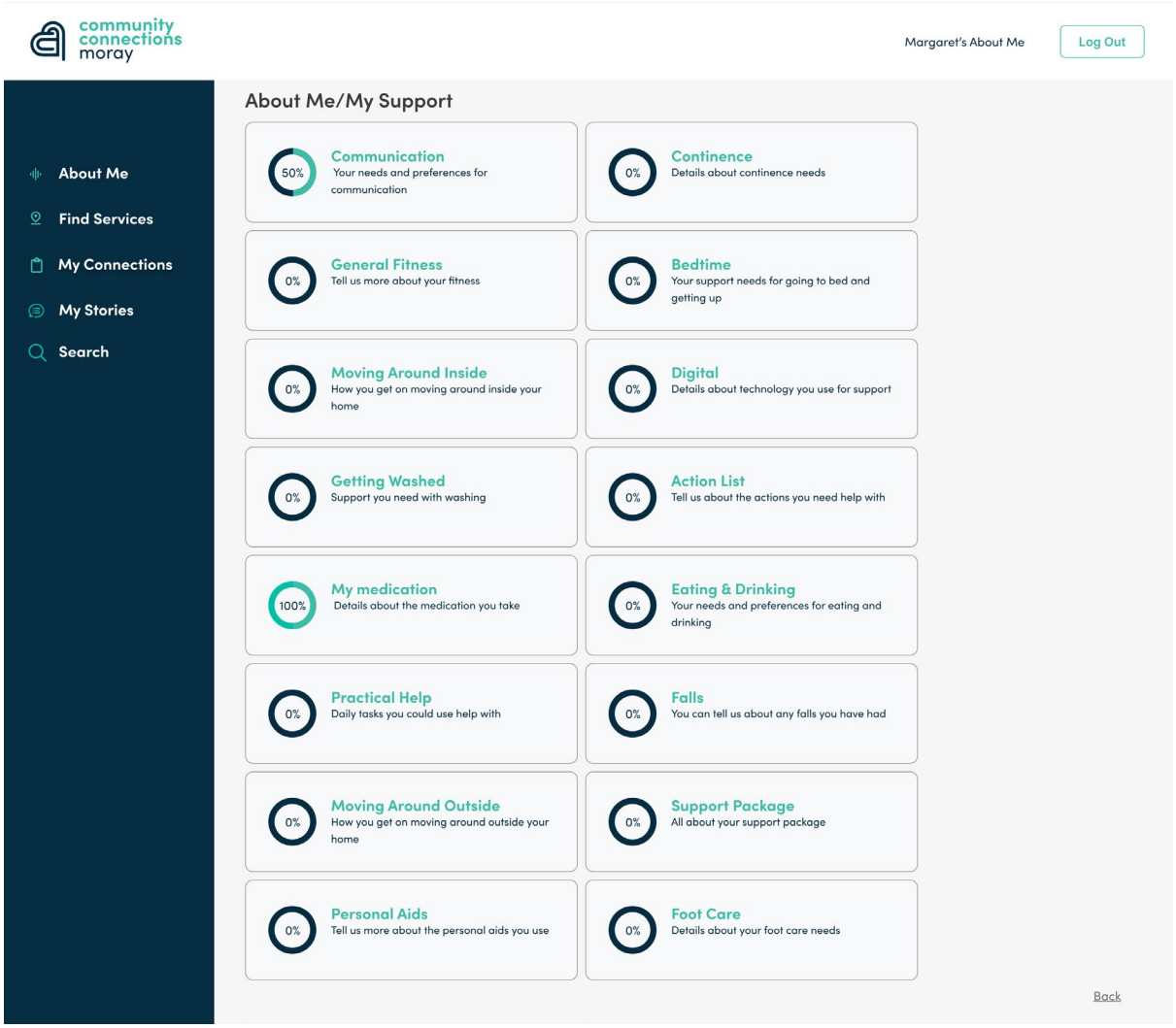

Figure 8: These are the sub-categories of structured data.

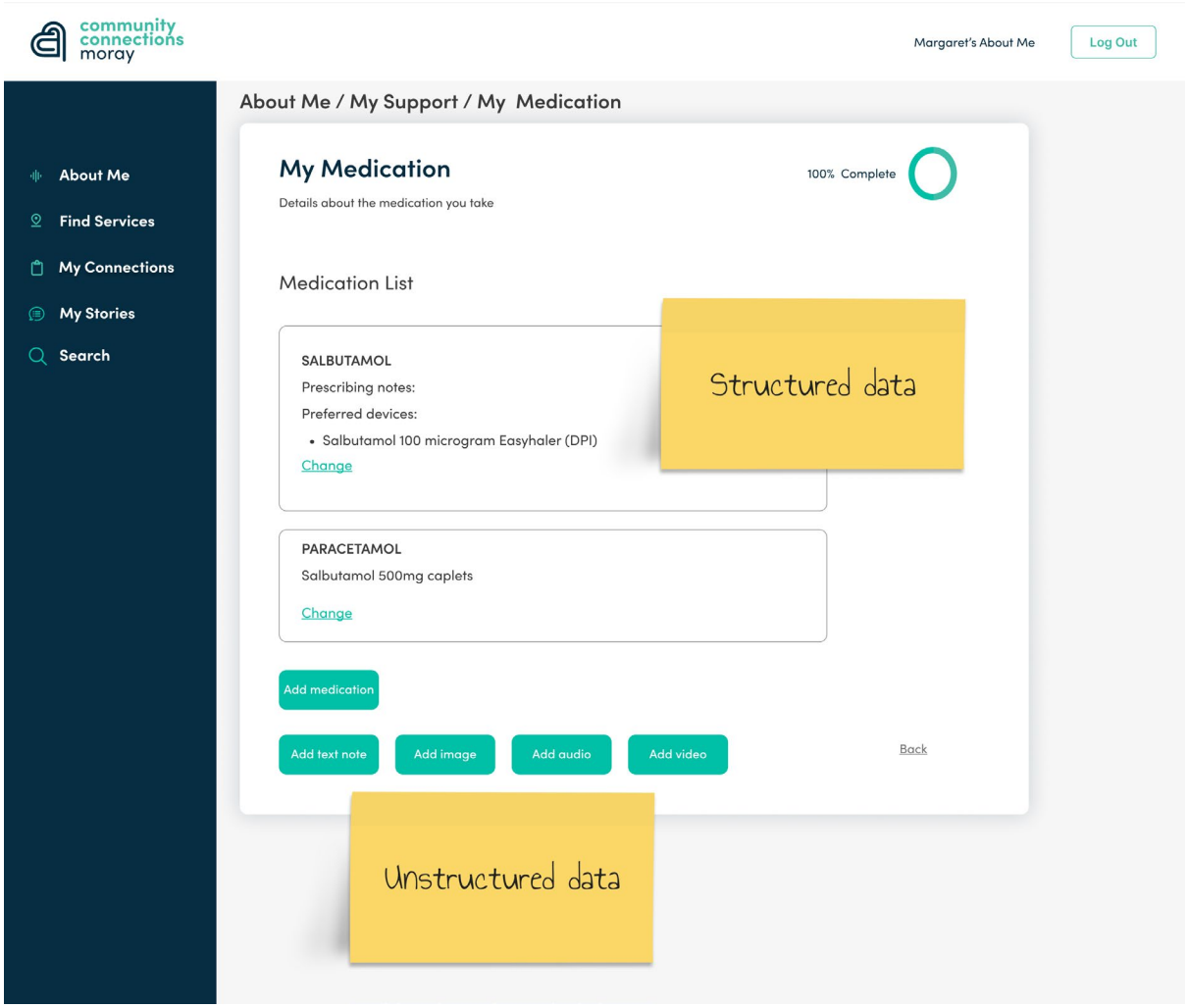

Figure 9: This is an example of some structured data. In this case, medications. For Requirement 3 we have buttons to add text notes, images, audio and video files.

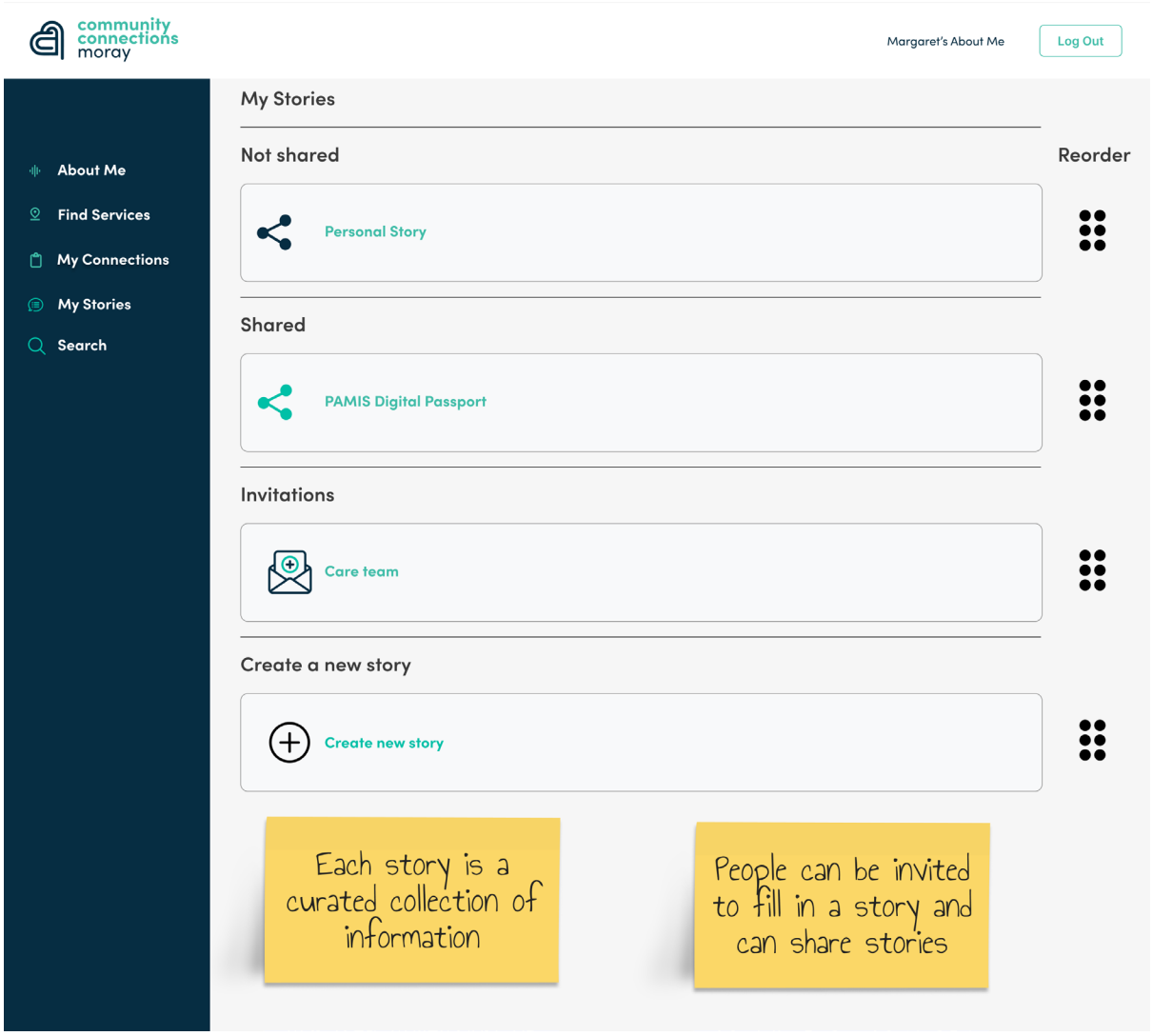

Figure 10: For this prototype and Requirement 1, we have introduced the concept of 'stories'. Each story is a collection of information, some chosen from the structured data and some unstructured text notes, audio, image or video files. Stories can be shared as editable or read-only. The order of information inside a story can be chosen and rearranged. A set of information that defines a story could be created by somebody else and sent to a person as an invitation to fill out that set of fields. For example, we might imagine PAMIS sending a 'Digital Passport' story to people wen they start filling out their first PAMIS Digital Passport.

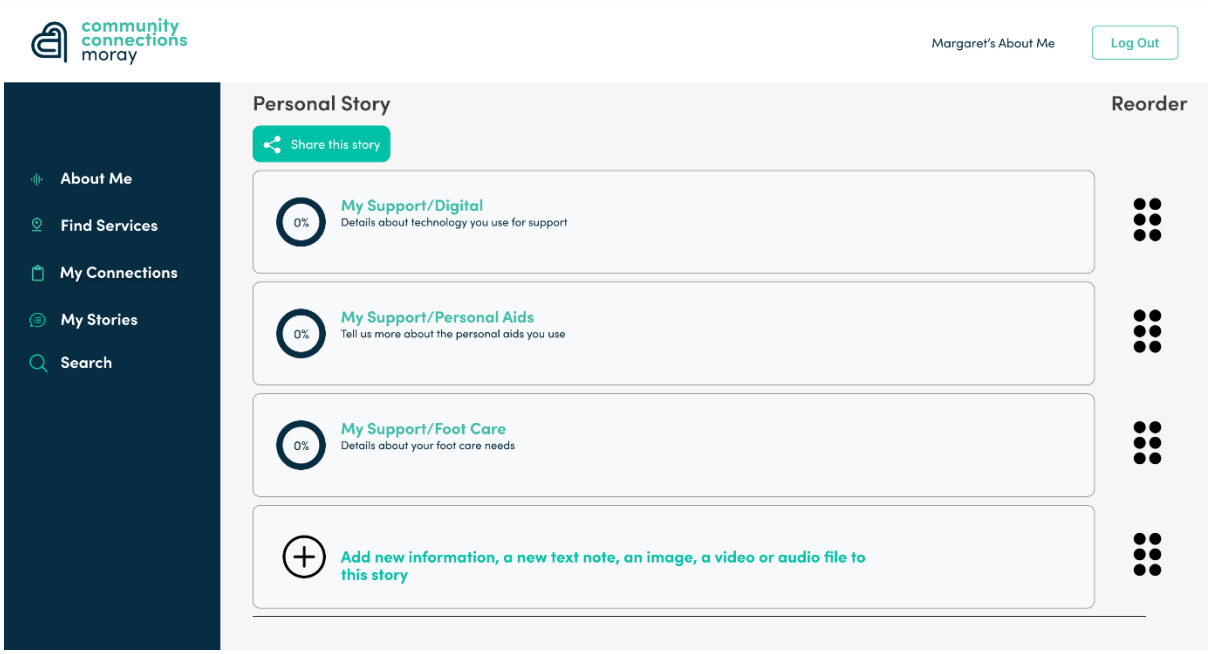

Figure 11: Here is a story with 3 items of structured data already in it. The items can be reordered. There are options for sharing the story with another person as editable or read-only (read-only would include something similar to PDF export for printing).

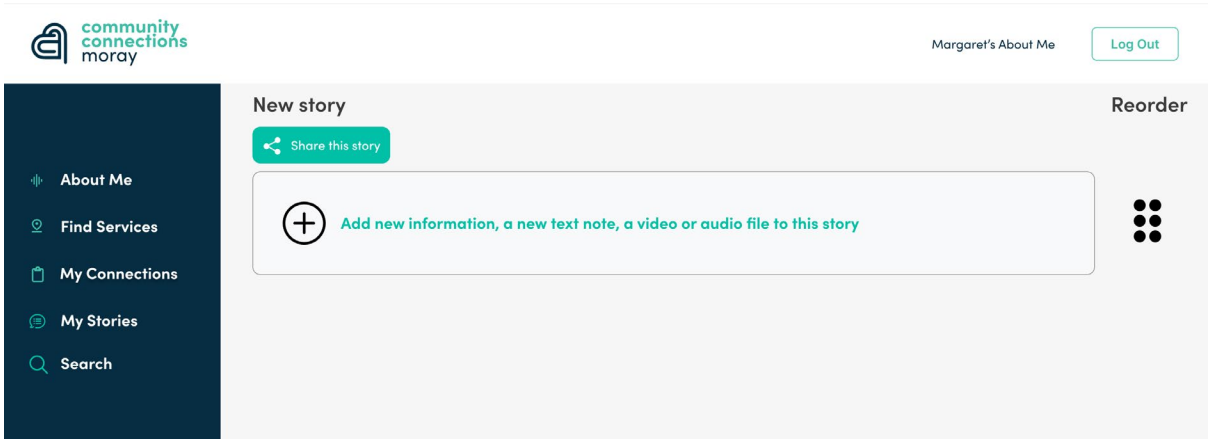

Figure 12: Here is an empty story ready to add information to.

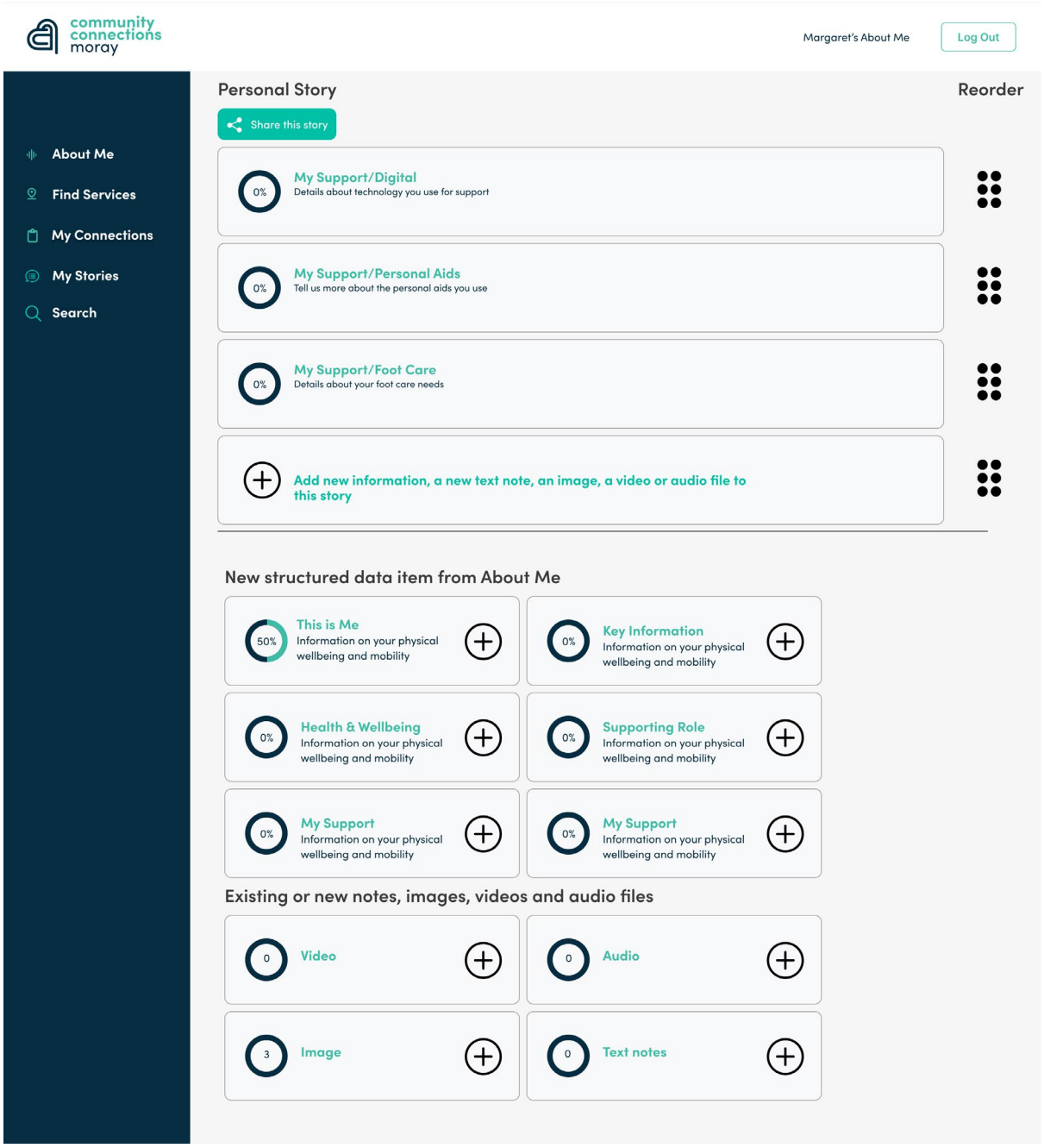

Figure 13: After choosing to add new information the person can choose to select existing structured data or add unstructured data. Note that unstructured text notes, audio, images or video can be attached to a structured data item.

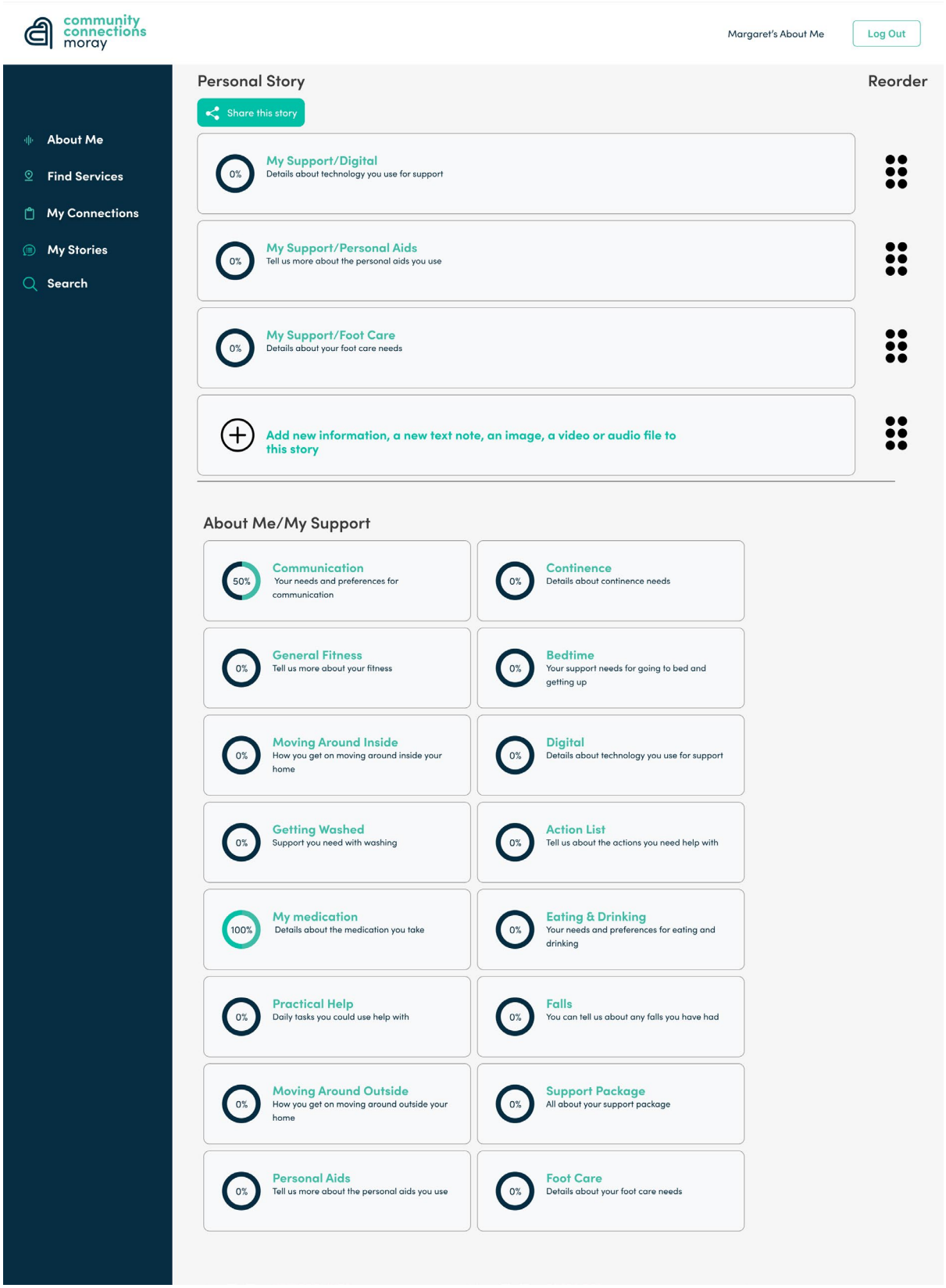

Figure 14: Here are the options for adding a new structured piece of data to this story.

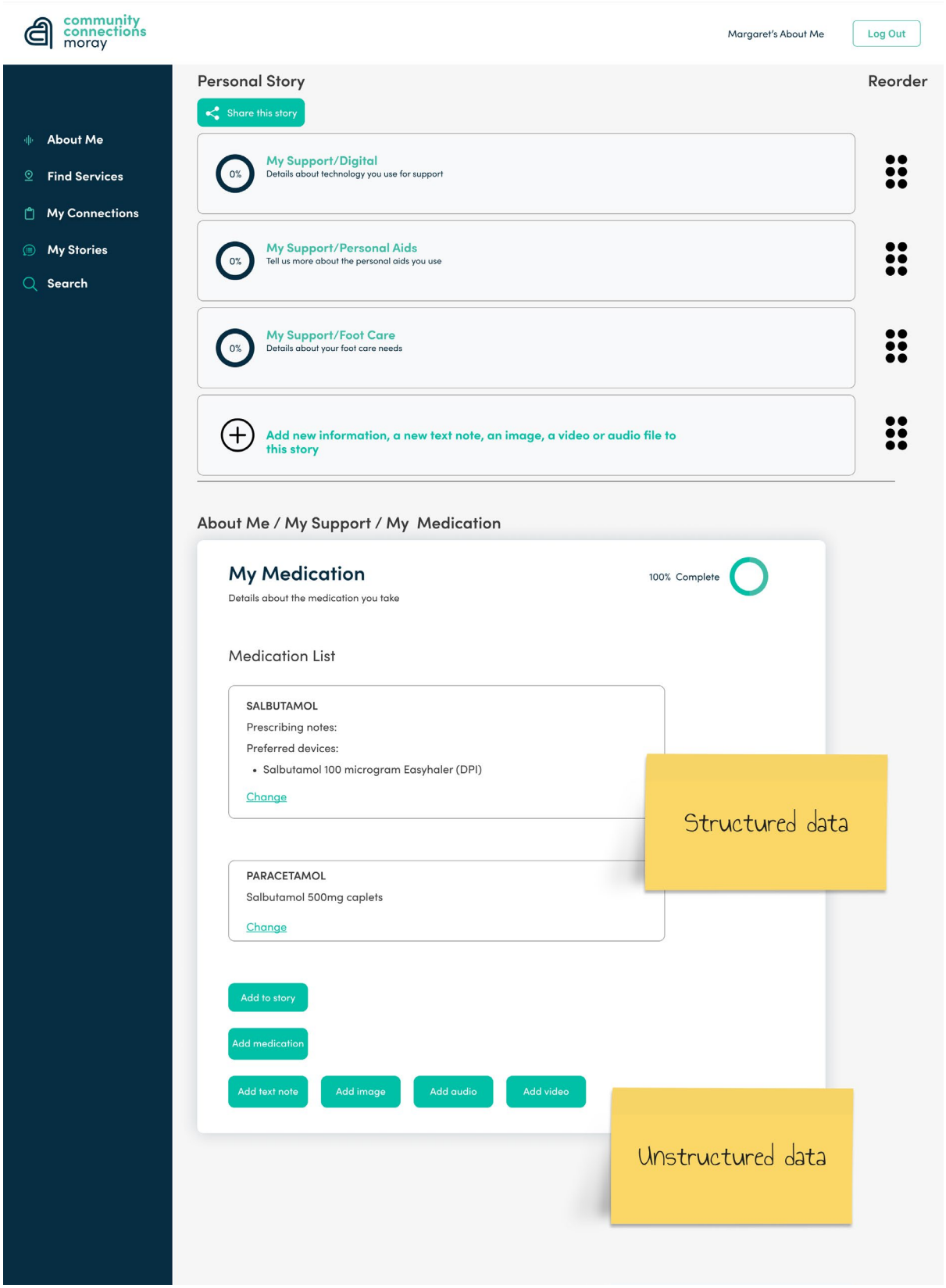

Figure 15: Here, the person can choose to add structured information about medication. It is worth remembering here that the benefit of this data being structured is that it can be read and shared automatically across systems.

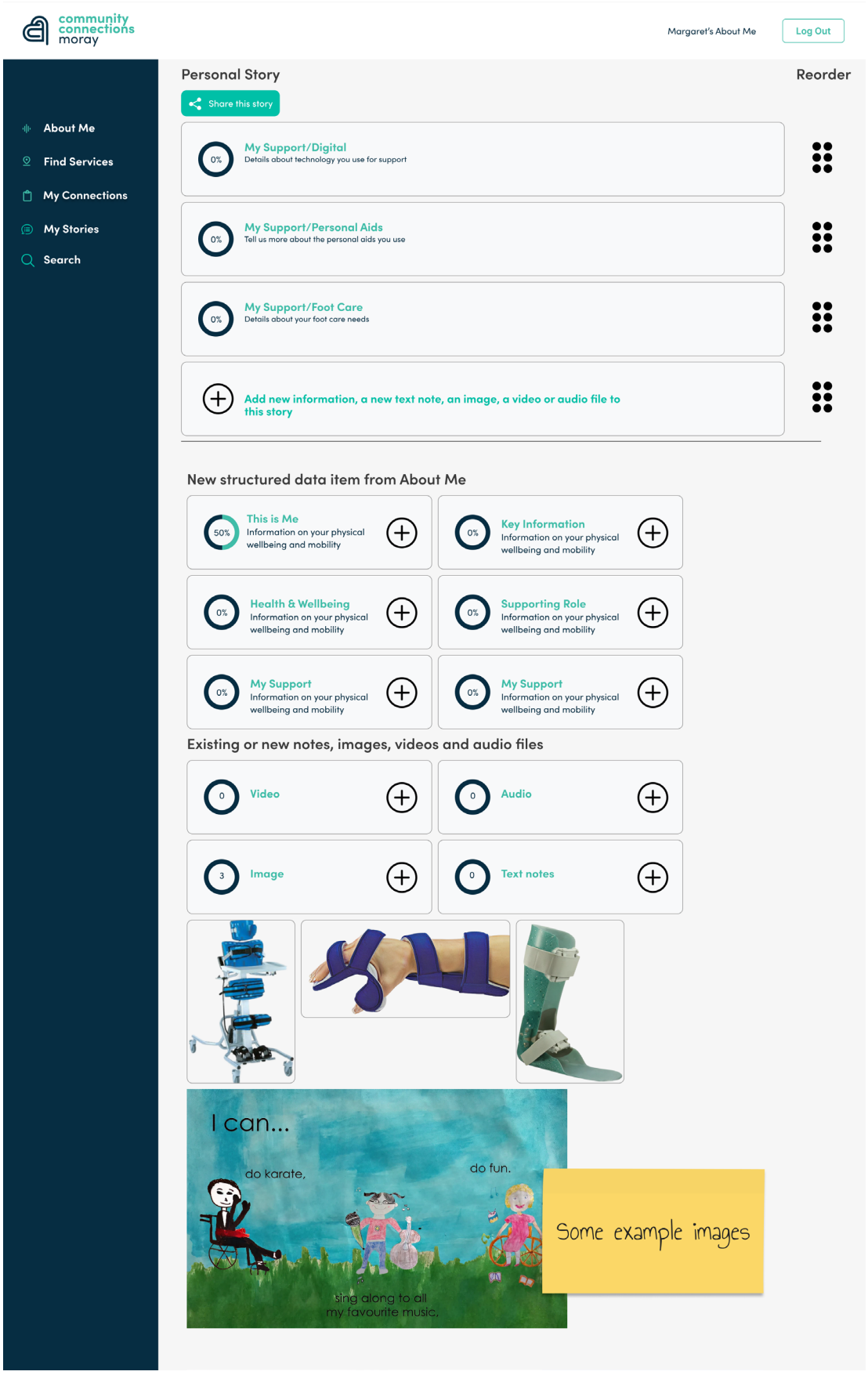

Figure 16: The person can choose to add new or existing text notes, images, audio or video files. Here, the prototype shows an illustrative selection of images to add.

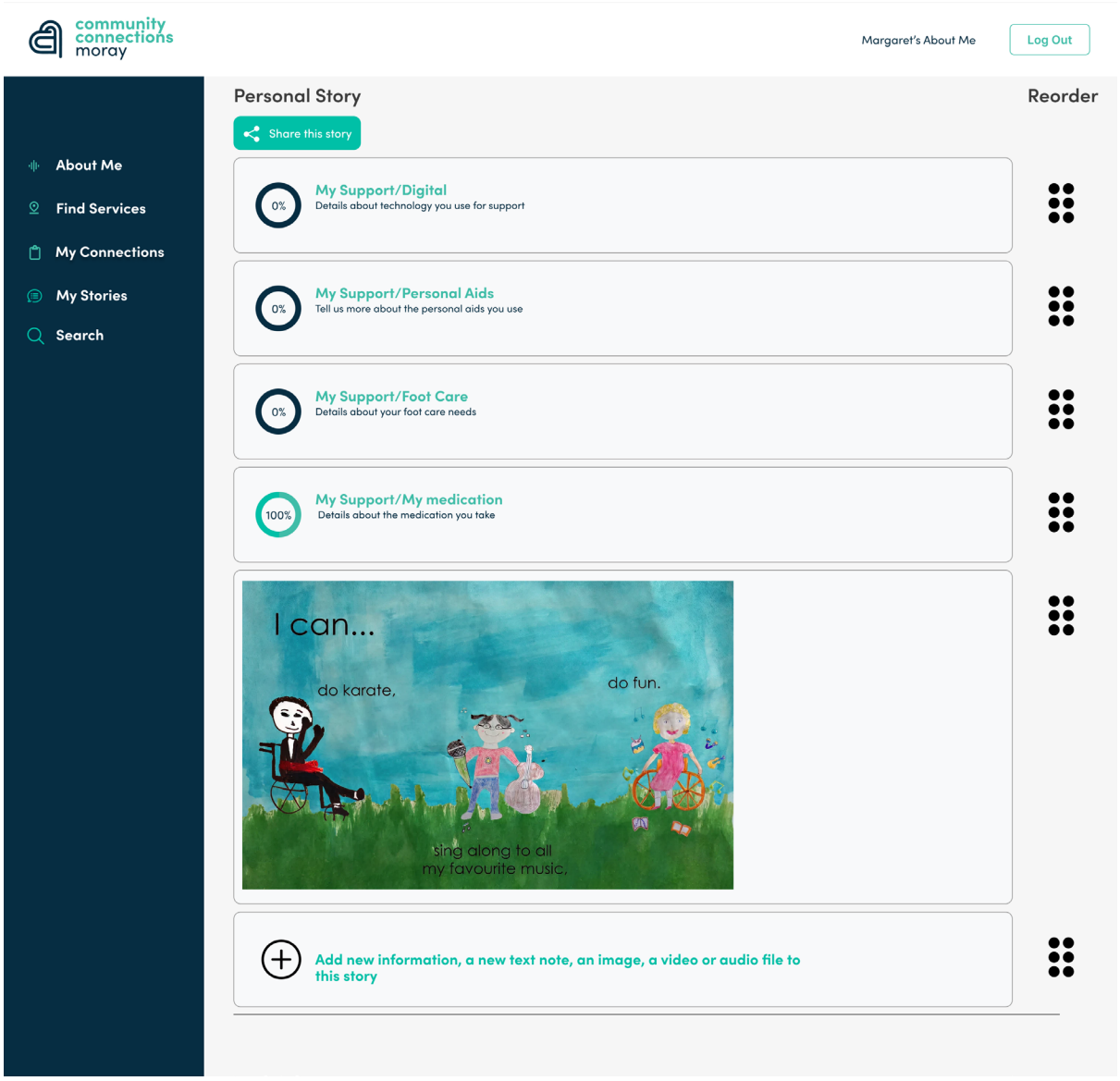

Figure 17: The person has added an image and their medication information to this story. A story can be as large as need be. Remember, the information can be reordered according to the person's preference.