Backpack

Personal Data Store

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Dr. Jay Bradley
Personal Data Store

What if all your personal records, including your relevant personal health and care records were held in one place that you control?
Unpacking the backpack

Using a Participatory Design approach to unpack:

- Explore the idea of a personal data store with end users
- Understand how it would change working practices
- Develop the concept and identify user requirements
- Experiences of people living with MS
- Challenges of navigating health and care services
Research Design

Lab 1

Mapping Key Moments

Lab 2

Proto App
Using the Backpack

Physio only used
Andys not aggregate

PIF
worst case
but may need
to do that to
get the correct benefits

Play how they are
but it is so important to fatigue.

More benefits if you do
positive role.

GAEAS
build your own team prototype

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## Findings

Overall values to guide the development of the Personal Data Store:

<table>
<thead>
<tr>
<th>Service Qualities</th>
<th>Safe, welcoming, understanding and knowledgable.</th>
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</thead>
<tbody>
<tr>
<td>Equity</td>
<td>Equitable able access to the information their health professional holds about them.</td>
</tr>
<tr>
<td>Depth of information</td>
<td>Presenting high level information with the ability to see and share the detail if required.</td>
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<tr>
<td>Secure</td>
<td>Reassuringly secure, however participants were pragmatic about the benefits, versus the risks.</td>
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<tr>
<td>Person-centred</td>
<td>The ability to reflect the goals, needs, personality and interests of the owner.</td>
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<tr>
<td>Anticipatory</td>
<td>Adaptive, anticipating the needs of person as their health and care requirements change.</td>
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</table>
I am in control of the data but I'm happy to share and make certain things available.
1) Mapping Interactions

**MS Nurse**
Jamie Ruby
ongoing support < 
last contact 06/01/17 <
Scheduled appointment 05/06/17

**GP**
Louise Plum
last contact 01/01/17 <
tonsilitis requiring antibiotic <
3 monthly blood test due 04/05/17

**Community Alarms**
David Black
assessment 08/09/16 <
alarm implemented <

**Amy Green**
Wife <

**Andy Green**
> Living with MS
> tonsilitis requiring antibiotic

**Neuro Rehabilitation**
Dr. Petra Lime
ongoing support <
last contact 09/10/16 <
Scheduled appointment 09/10/17
2) Health Story
3) Smart Form Filling

In Case of Emergency

Andy Green
> Last updated 1st Mar 17

Emergency Contact

Amy Green
Wife
(Next of kin)

- Power of Attorney in place for Amy Green
  Registered with The Office of The Public Guardian (Scotland) - 12/12/2016

- Transfer access of my Backpack to Amy Green
  including:

  Access All Areas
  Restricted View (specify)
  Restricted Share (specify)
### 4) Tools for the Specialist Nurse

<table>
<thead>
<tr>
<th>Patient Name</th>
<th>Change (priority order)</th>
<th>Expand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andy Green</td>
<td>&gt; admitted to hospital May 9th 2017 (Dr Grays, Nurse J. Holmes)</td>
<td></td>
</tr>
<tr>
<td>Esme Lime</td>
<td>&gt; referred to Physio (GP, Dr. Black)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; appointment scheduled for May 26th 2017</td>
<td></td>
</tr>
<tr>
<td>Rosie Smith</td>
<td>&gt; referred to Occupational Therapist (GP, Dr. Smith)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; home visit scheduled for June 10th 2017</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rosie needs to be assessed due to new symptoms of numbness and problems with balance. Home environment may need modifications to reduce risk of falls.</td>
<td></td>
</tr>
<tr>
<td>Jen Pink</td>
<td>&gt; Husband has been admitted to hospital (Jen Pink, May 24th 2017)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; Home care support requested social work assessment pending</td>
<td></td>
</tr>
<tr>
<td>Jules Damson</td>
<td>&gt; Tonsilitus (GP, Dr Brown)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; Antibiotics prescribed (GP, Dr Brown, May 24th 2017)</td>
<td></td>
</tr>
<tr>
<td>Dan Forrest</td>
<td>&gt; Community Alarm requested (Joanne Forrest, May 23rd 2017)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; Home assessment scheduled June 1st 2017 (Alarm team, Kay Jones)</td>
<td></td>
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<tr>
<td>Betty Blue</td>
<td>&gt; Community Alarm requested (Betty Blue, May 22nd 2017)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; Home assessment scheduled June 1st 2017 (Alarm team, Kay Jones)</td>
<td></td>
</tr>
</tbody>
</table>
Thanks

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