Backpack

Exploring how integrating data from different parts of the system through a person-held data store ('Backpack') could transform the way we access health and care.

Using participatory design approaches, we involved people living with Multiple Sclerosis (MS) and health and care professionals who support them in considering how person-held data could transform interactions with health and care.
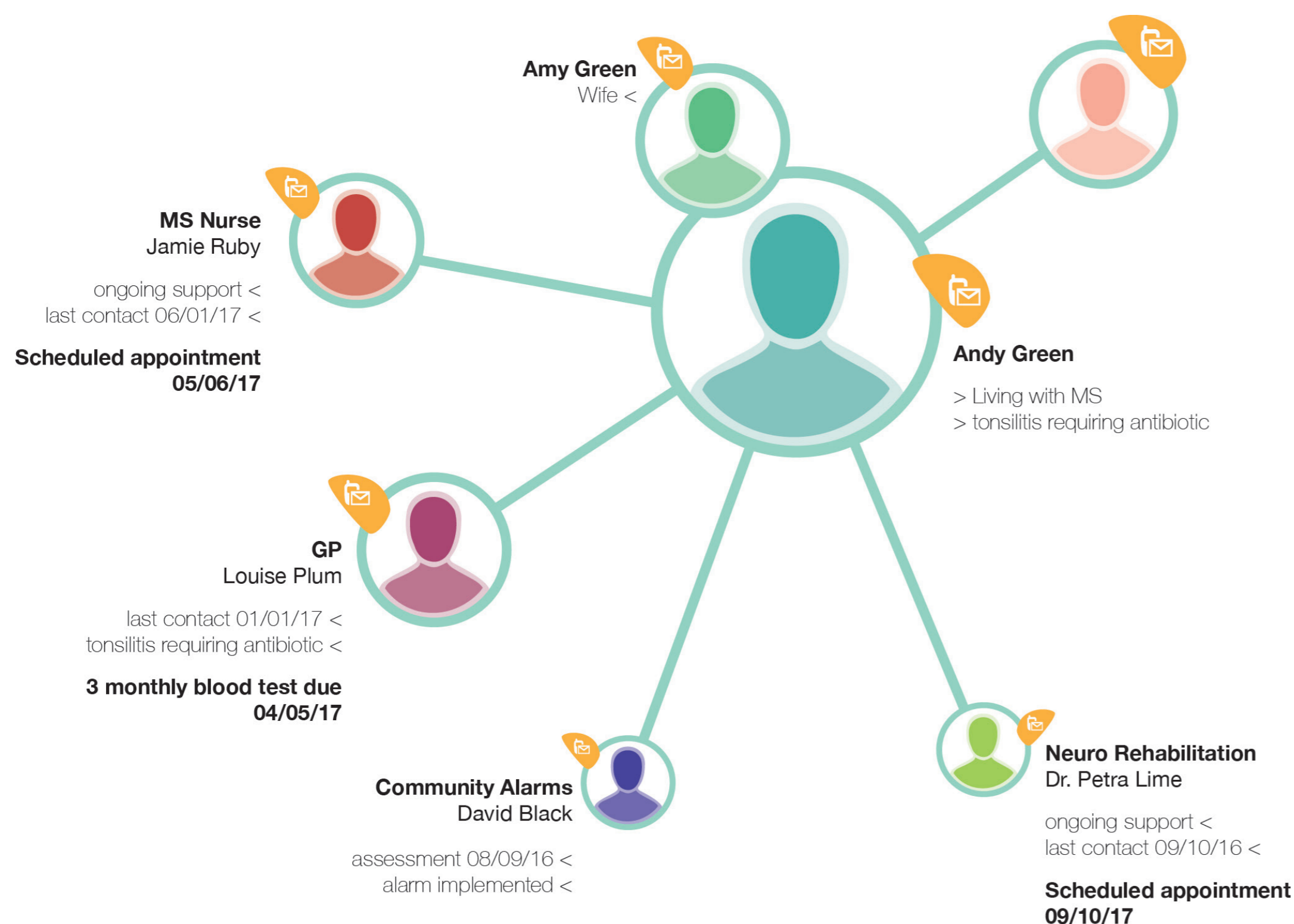
We used a paper-based tool to support people living with MS to think about how their information could be stored, connected, shared and protected.

Through this, we learned about the frustration of telling a complex and often emotionally difficult "health story" every time they engaged with a new professional. We discovered that data stores should be centred around the fun and fulfilling parts of life. And we heard about the challenges of keeping track of all the different professionals who may be involved, something that was echoed by health and care professionals.

"So there's a team of support there but I kind of needed to hold in my head that these are all people that can be accessed..."

photo © Louise Mather

Amy Green
Wife <

MS Nurse
Jamie Ruby

ongoing support <
last contact 06/01/17 <

**Scheduled appointment
05/06/17**

Andy Green

> Living with MS
> tonsilitis requiring antibiotic

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 <

Neuro Rehabilitation
Dr. Petra Lime

ongoing support <
last contact 09/10/16 <

**Scheduled appointment
09/10/17**

Translating Insights into Concepts

Many fundamental concepts emerged from this project which have become the building blocks of our work at DHI. The insights and ideas shared by people living with MS and health and care professionals in Moray have resonated across the Scottish health and care landscape.

A key concept we are exploring is how to map care interactions around the person to overcome the challenges of navigating a complex health and care system. We are exploring how this can be communicated as circles or timelines of care.

One participant proposed the concept of a self-curated "Health Story" enabling the person to share their story in their own words, using video or written narrative, supported by key dates and facts. This concept has been explored and realised in several subsequent projects and is emerging as a key tool in enabling person-centred care.

"I have given up looking for this care team and (I'm) realising it's got to be a virtual one."

Digital Health & Care Innovation Centre