Digital Health:
Are we getting the right patient perspective?

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As the digital health markets continue to converge, new products and services must be aligned to healthcare policy, regulatory requirements, research needs and, most importantly, a more demanding public.

The sub-text in government thinking, especially in developed economies where "health care institutions have overshot the level of care most patients need"[1], is all about improving value. Investments in change will only be made if health economic arguments are made to maintain or improve outcomes whilst lowering costs.

The following statements provide a good indication of where healthcare is heading:

- An emphasis on patient.
- An emphasis on prevention rather than cure.
- A shift from acute care to integrated home and community care.
- Being better able to deliver care equitably and where most needed.
- Helping people to better look after themselves.

These policies echo what academics in health management have been saying since 2013:

"We must move away from a supply-driven health care system organized around what physicians do and toward a patient-centred system organized around what patients need. We must shift the focus from the volume and profitability of services provided—physician visits, hospitalizations, procedures, and tests—to the patient outcomes achieved." [2]

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[1] Clayton M Christensen, Richard Bohmer, and John Kenagy, Strategies for Healthcare, Harvard Business Review

[2] Michael Porter and Thomas Lee, 2013 Harvard Business Review

Where to start?

Aligning with these aims and objectives is vital when investing in new digital health products and services. And, because we are trying to move away from the existing fragmented, clinical and institutional model, it doesn't make sense to start our new digital journey by aligning too closely with existing health services, pathways or software systems.

The new emphasis is the patient, so Patient Advocacy Groups are a good place to start. In the UK we are lucky, we have a well-developed charitable sector whose sole reason for existence is to represent the best interest of their population. These charitable groups are ideal organisations with which to work: to discuss needs as well as develop and test ideas. They can also benefit from the commercial support that digital health will be able to provide. Importantly, these are also organisations the public trust to protect their interests.

Over the past couple of years, we have worked with two types of health partner, one is an advocacy group that has a national team of community nurses, and another is an amalgam of delivery and research (a university & teaching hospital).

What do patients want?

Using this partner approach, we have started to create our integrated digital health solutions.

For, example in 2018 we developed an integrated digital service in Mild Cognitive Impairment (MCI): providing patients with ongoing testing, feedback and support - and a community monitoring type service with ongoing identification, recruitment and assessment. This Digital Patient "Companion" was created to provide an alternative (digital care) pathway for patients to follow. There was no physical clinic or community-based pathway prior to this. The new digital 'pathway' was designed to keep people and their families in the loop with their local services (sharing their data), while allowing them to monitor the situation themselves with standard validated tests and tools.

We call the person or patient part of the solution ("the app bit"), the disease or wellness "Companion". It is designed to be holistic and empowering. It puts people at the centre, along with control - and collects the data that is most important to them: outcomes. This is the opposite of how health services currently work, and almost certainly feel!

If the user does not want to share their data – they can choose to switch off sharing. If they don't wish to see feedback, say in the form of an ongoing graph of their results, they can switch that off too.

The holistic and empowering also comes from the platform's openness and the types of data collected. The most important data being the evidence that healthcare is delivering what patients and families want - which is Patient Reported Outcome Measures or PROMs. According to the National Quality Forum, PROMs have been defined as:

'any report of the status of a patient's condition that comes directly from a patient without interpretation of the patient's response by a clinician or anyone else.'

These tools enable assessment of health status for physical, mental and social well-being. PROM's can be used to improve: health delivery, personal management of the condition, and research studies. They provide unique information on the impact of a medical condition and its treatment from the patient's perspective.

To start on our journey of understanding the patient perspective, we worked with partner organisations making educated best guesses. What would people want and what would motivate them to keep engaging? The following is what we assumed, and then went on to test:

✓ "Use my data to keep me well and out of hospital."

✓ "Assume I want to be kept well informed and in control of my own health data."
✓ "Use my data for the greater good."
✓ "Give me access to new or novel therapies (clinical trials) – should I want it."
✓ "Enable me to care for myself with the support of family and close friends."

Every disease or wellness area also has some specific requirements that people are looking for. In the MCI "Companion" it was brain testing, and a very specific family support component. In Mesothelioma we are looking at (amongst other things) easier access to clinical trials and how-to better support patients with their finances.

We then work our ideas into a prototype. We like to create a working tablet and smart phone facsimile using special software so that users can experience exactly what a "Companion" would be like in their hand. We have found this 'straw man' approach the perfect way to test a design – and much easier for people to critique.

Patient advocacy and the health services often discuss issues, approaches or new clinical pathways in open forums to which they invite the public. These are called Public Patient Initiatives or PPIs. It's here that we bring our 'straw-man' prototype for people to engage with (and if they want, "pull it apart"!) Through these discussions, and before we've gone through all the expense of developing a fully functioning tool, we get a good idea of how successful our "Companion" would be – along with our first iteration at re-shaping it!

We have developed designs for two "Companions" now. One we have already put through a PPI process, and the other we are about to.

What did patients think of our "Companion"?

The PPI day spent time explaining the "Companion" and letting people play with it. We then had round table discussions to explore likes and dislikes, what should be added what should be removed or changed.

Following this we handed out a questionnaire. We asked three questions:

1. *What is it that makes the "Companion" something you would like to use?*
2. *How often would you be willing to engage with the questionnaires within the "Companion"?*
3. *How long do you think you would engage with the "Companion"?*

Summary findings

The PPI demonstrated to us that people were hugely supportive of the digital "Companion" idea. As you can see from their responses to our questions, they agreed very strongly with our statements for why they would want to engage, and were more than willing to enter data into the tool regularly and over a considerable period of time.

See next page for the results of the PPI Questionnaire.

Results for Dementia / MCI Public Patient Initiative (PPI)

The Dementia / Mild Cognitive Impairment (MCI) Public Patient Initiative took place May 2019. People were invited in couples. One of each couple had either a family history of dementia, or a concern that they might be experiencing some mental decline but did not currently have a diagnosis of dementia. The total number of people that took part was approximately 18 (or 9 couples).

Note: The numbers in the tables below indicates how many people ticked that box. (The total n was 9). The colour has been added so you can more easily see the most popular answers.

What is it that makes the "Companion" something you would like to use?

Question	Very unimportant	Unimportant	Neither important or unimportant	Important	Very important
connects into services/care	1	2		2	4
keeps you informed about yourself	1			4	4
Knowing your data is helpful for research				2	7
Potential early access to new/novel therapies			2	1	6
Enables you to help yourself	1		1	2	5

How often would you be willing to engage with the questionnaires within the "Companion"?

Area of Questionnaire	Every day	Every 7 days	Every 14 days	Every month
Memory check (3 mins)		8		1
Mood check (3 mins)	2	6		1
Quality of Life check (3 mins)		6	1	2
Quick symptoms (< 1 min)	4	5		
Quick Lifestyle (< 1 min)	4	4		1
A symptom check (6 mins)		2	1	3
A task/activity check (8 mins)		3	1	3

How long do you think you would engage with the "Companion"?

Period of time	3 months	6 months	1 year	Indefinitely (> 1 year)
How long would you engage with the tool?		2	2	5