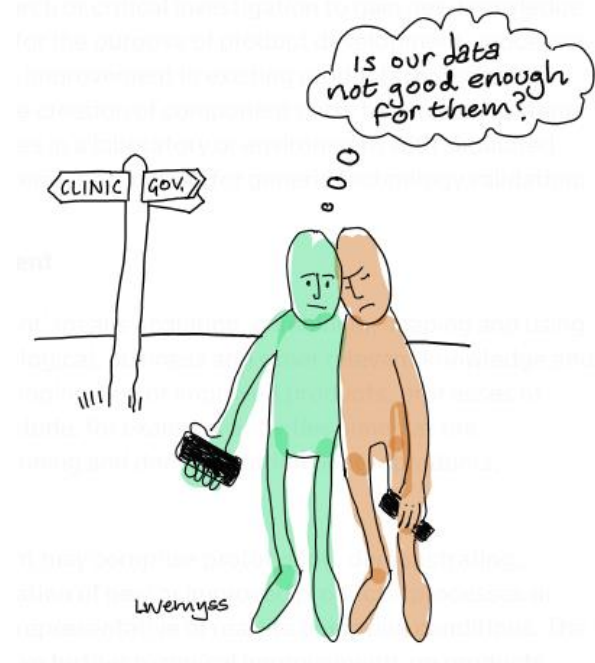


## Digital Health: Are we realising the promise of digital health?

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*Amongst industry experts there is almost total agreement that the future of healthcare is heading for much greater digital integration.*

So, the question is arguably not 'if' or 'when' these changes are arriving, but 'what' they should look like, and 'how' to leverage any differences. We now have an opportunity to make new products and services that are truly compelling and impactful. It is an exciting time.

Integrated digital healthcare must be thought about in terms of four customer groups:

1. people or health care consumers,
2. the healthcare industry, (e.g. Pharma, diagnostic companies, etc.),
3. health services or providers, and
4. governments and regulators.

As these customers or markets overlap, working across them becomes increasingly complex, not least because products or services will in future need to satisfy all of them

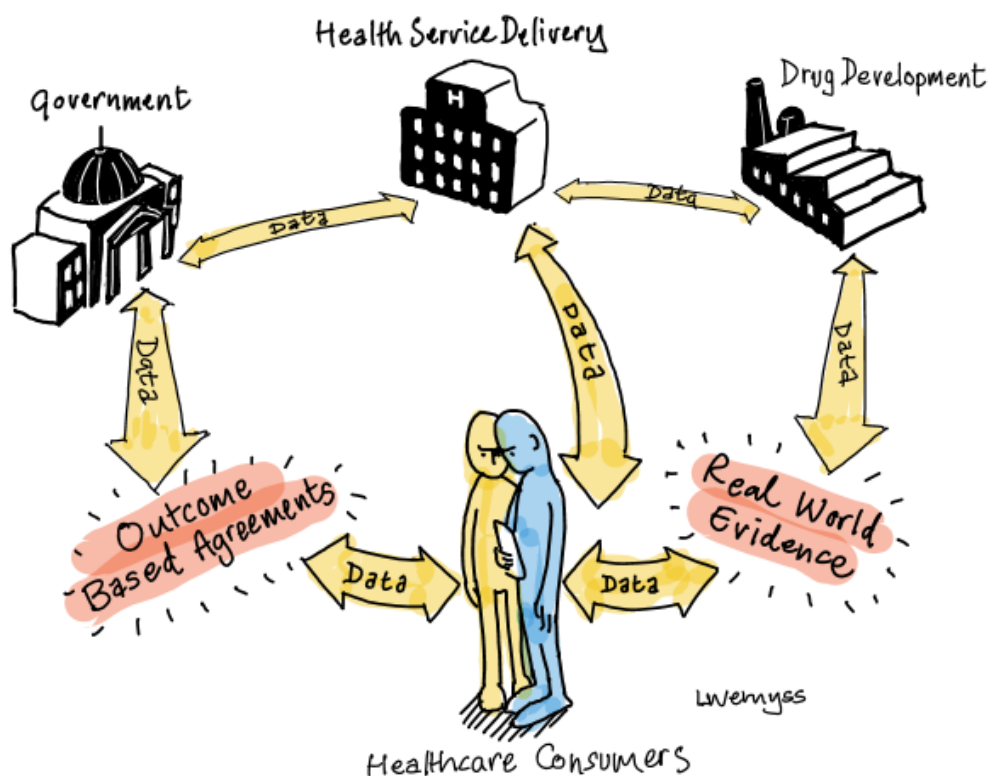


Figure 1. Can we realise the promise of integrated digital healthcare

simultaneously if they are to succeed! However, knowing how to navigate the overlaps offers a chance to both fix current issues as well as open doors to significant new opportunities. (See Figure 1.)

## Challenges for the Healthcare Industry

The growing world-wide requirement to complement Randomised Clinical Trials with real-world evidence is expanding a market estimated to be in the region of \$2bn by 2026<sup>1</sup>.

The existing methods for collecting, harnessing, and delivering real-world evidence is however changing, as new digital models emerge. These models need to gain traction,

as to date the healthcare industry is still replicating what it's done in the past: using data from isolated secondary data sources, generating customised prospective studies or even continuing to use outdated inefficient data collection methods such as pen and paper. A good example of this is the Product or Disease Registry that Pharma routinely set up to demonstrate Safety and Effectiveness. (For example, when following the launch of a new product). In comparison with an integrated digital approach, these registries are problematic. They:

- Are high cost, with arguably lower quality data.
- Waste time and investment through a 'fire and forget' data collection culture

<sup>1</sup> [Zion Market Research](#)

- being implemented for specific research purposes and then stopped.
- Take a long time to set up, collect and publish the data in comparison with having the data always to hand.
- Cannot easily be established to link into other data sources – which could add significant value to the project. For example, integrating diverse new datasets: e.g. Bioinformatic databases or existing Electronic Medical Records across an entire health service.
- Can find it difficult to create the necessary scale within the project resource, (i.e., depth, access, geography or period).
- Are unlikely to have the ability to provide ongoing evidence required for Outcomes Based Agreements (OBAs) - the new model for pricing & reimbursement between industry & payers.

## Opportunities for the Healthcare Industry

Integrated digital platforms would need to be set-up to ensure research services are part of its DNA. They would employ novel “multi-client” models to provide cost efficiencies. These multi-sponsor models would share investment costs, address concerns about vested interests, and will ultimately provide publications that carry much greater regulatory or market access impact.

Also, as research projects are undertaken and able to align with a more integrated digital infrastructure, they will offer opportunities to adapt over time, providing ongoing enhancement of data quality and the ability to grow participation. This creates a more collaborative project path, meeting the needs and ambition of all stakeholders. For researchers it will be especially useful in areas of rare disease where it is often difficult for

studies to achieve the scale required within a manageable budget. For the health service it will be a great way for attracting outside investment into disease areas that are often overlooked.

*For example, DaSH Global are currently helping set up an integrated digital platform in mesothelioma where we are working with patient advocacy to engage new industry sponsors. This is to support a new Community based Patient Companion application. We will start with recruitment at local level for 6 months, but within the space of a year we plan to scale up to include ALL existing & new patients nationwide.*

This “open platform” approach will also facilitate third parties being able to plug in external validated instruments and consumer digital health tools such as wearables. As these projects gain greater credibility and interest so more data resources will be permanently plumbed in, including national IT infrastructures such as Electronic Medical Records, (EMRs) and genomic databases.

## Challenges for Healthcare Consumers

Over the last two years the use of consumer digital health tools: i.e. Apps, Wearables, Home Diagnostics and Wellness programs is declining globally for the first time since 2014. (See Figure 2.) This is during a period when digital technologies, social media and information technology has never been as popular. Despite a huge initial uptake in measuring wellness and wanting to become involved in health management, users now cite “concerns about my privacy or data security” as the No 1 barrier.

Also, people when entering their data into Apps, or wearables want to know that, should they choose, their data could be used and evaluated at a wider clinical level. In this way

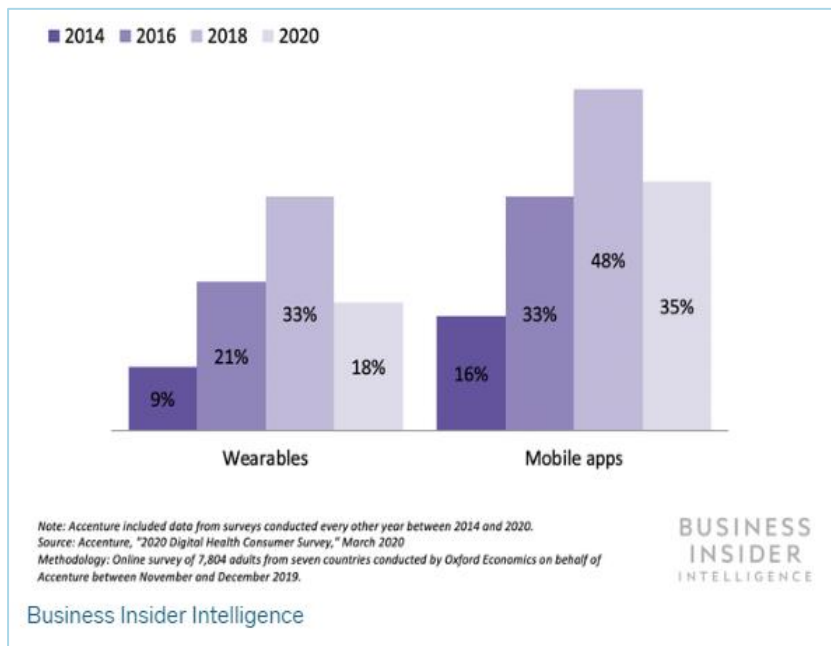


Figure 2. Consumers' Use of Digital Health Tools is Declining Globally

they would be more actively investing in their own healthcare or wellbeing.

In the UK, mobile apps or wearables that integrate into clinical pathways are very few and far between. The patients we spoke to were surprised by this. This is all the more surprising as the research benefits of all this data are obvious. If routinely collected and used in co-ordination with health services such data would also support current government policies of helping drive better community care, ensure equity of provision and help to make prevention a reality (through better predictive modelling).

If not done correctly, however, many clinicians and general practitioners fear an avalanche of data might have the opposite effect. It is this fear of causing more unwarranted activity, along with needing to find the investment of time and money to turn the data into useable evidence that is currently holding back its wider acceptance.

## Opportunities for Healthcare Consumers

*DaSH Global spent much of 2018/19 working with Manchester University Hospital looking at designing what a community digital companion might look like for people with early dementia or Mild Cognitive Impairment (MCI). This is a new clinical pathway with no routine clinical data available anywhere in the world at present. We tested our design at a*

*Patient & Public Involvement (PPI) where potential users and carers can: Influence their own care and treatment and to have a say in the way new services are planned and run.*

*We wanted to know the level of interest and the degree to which patients and family members would engage with a digital companion that would allow them to regularly test their cognitive abilities, as well use validated instruments to report on symptoms and quality of life. We asked:*

- ✓ *Would you use such a digital companion at home on an on-going basis?*
- ✓ *How reassured are you by the fact that the data is being collected by the health services?*
- ✓ *How often or regularly would you be prepared to enter data?*
- ✓ *Are you happy for your data to be used for research?*
- ✓ *Would you use it in the hope of gaining early access to clinical trials?*

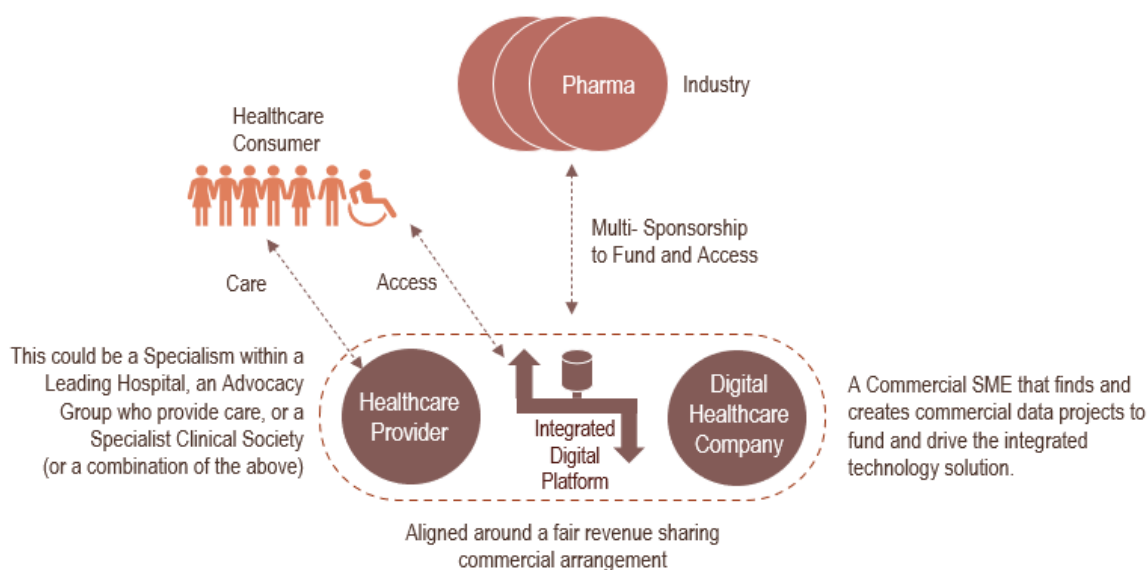
✓ *How long would you engage with such a tool for?*

*The response to every question was almost universally positive, with all patients being extremely interested in a digital health trial.*

[\(See our article 2 for greater detail on this PPI\)](#)

*and digital technology; and, getting the most out of taxpayers' investment."*

Worldwide, health policy is deciding to put patients at the centre and has declared the importance of using digital health to better marshal resources to those in greatest need, to help predict and prevent admissions, and to



Schematic: what a Collaborative Integrated Digital Health Project looks like

Figure 3. How might this look in reality

### Challenges for Health Service Delivery

Even before COVID-19 arrived, developed economies were facing a ‘perfect health care storm’: spiralling demand, an aging population, and a reduced ability to pay.

After COVID their strategic approach is unlikely to change. The UK’s Long-Term Plan for example, published in Jan 2019 said:

*“...things need to be approached differently: preventing illness and tackling inequalities; investing in staff; making better use of data*

support research with a much richer and more complete data set. Together these changes will help drive significant improvements.

### Opportunities for Health Service Delivery

Taking this all into account, there is both a social and economic need to drive a new holistic approach - where health delivery meets the growing and unsatisfied needs of health consumers, healthcare services, industry and governments. In other words, all stakeholders must grasp the opportunity to collaborate: to create health information eco-

systems that we can embed into our communities and that support the development of new interventions and ways of working.

These will include a new generation of data networks, this time not built into the institutions of health, but built around people and communities who either want to remain well, or who are living with a disease. These “wellness or disease data platforms” must put patients at the centre – and exchange data with relevant partner organisations. We are calling these disease area health platforms: **Digital Assessment Xchanges (DAX)**.

The seven key ingredients in creating **DAX** are:

1) **Choose the right collaborative partners:**

These are partners that have the appropriate set of skills and capabilities to drive the project and make it happen. (See Fig 2. Schematic) These would include:

- ✓ health care delivery providers that have sufficient national influence, can afford the time to clinically engage, have access to the right patients, and have sufficient decision-making autonomy;
- ✓ industry partners that can make significant investment in terms of project funding, additional technical know-how and can generate revenues to help support healthcare services;
- ✓ a catalyst to spring this into life and to act as an independent ‘ringmaster’. A partner with the ability to find funding, align and persuade existing services of the future benefit, to take risk on building a digital health vision, and to manage a return on investment. This is where new digital health care companies are needed. This is especially true where industry is careful to invest, where success doesn’t look so certain, and where

healthcare services need to be busy doing their day-jobs.

2) **Ensure the collaboration is based on a fair and equitable commercial arrangement.**

Commercial collaborations need to be based on trust, where there are no conflicts of interest, and where contracts only affirm fair ongoing arrangements.

3) **Make the aims and objectives align with new health policy.**

Allowing patients to take greater control of their own data and making them part of their own medical care is a future goal of healthcare policy. In general, there is no routine collection of Patient Reported Outcomes (PROs) within standard clinical practice and in addition this is not collected and linked back into medical records when patients are at home outside the clinical consultation. Consequently, an essential aim of new digital healthcare models is to maximise the engagement of patients and those who care for them (family, community nurses or GPs).

4) **Maintain public trust through good data governance and commercial transparency.** This is achieved by:

- ✓ working through an ethical committee;
- ✓ working with an appropriate health partner that the public trusts; (i.e. an advocacy group / a university hospital trust / a prestigious clinical society)
- ✓ adhering to Health Data Guidelines, and all National Information Governance rules;
- ✓ ensuring no single industry research sponsor has any sole right of access and that all public bodies such as University Hospitals are allowed free access;



- ✓ re-investing monies back into the health sector.

- 5) **Develop a commercial eco-system around the data.** This would be via healthcare industry funding of the platform and subsequent research projects derived from its data.

It would use a multi-sponsorship approach where all companies could gain access. Health Service providers do not have the finances or the risk-taking culture to invest the sums needed. The Healthcare Industry on the other hand is able to invest, is used to taking risk and needs to invest to provide more accurate and cost- efficient data to support new medical interventions as it enters into ever harsher regulatory environments. In addition, the Healthcare Industry is in a better position to invest, as opposed to using public monies, as an ongoing data economy (or eco-system) will be better able to adapt and sustain the needed developments.

- 6) **Start simple and small and plan for growth.** It is important not to rush into software development. Projects succeed based around a collaborative approach and good design. By this we mean: choosing where in the pathway a tool should be placed, what data needs to be collected, and deciding if and what feedback and support patients & healthcare delivery need. As this is a new community-based health service offering, it is better to keep it simple and start small. A Minimal Viable Product – followed by any necessary adaptations - before scaling-up. This will ensure early success and a more sustainable long-term future.

*N.B. IT projects in the public sector, particularly in the health service, do not have a have a great history of success. There are many reasons for this, but two obvious ones are either: reproducing existing flawed processes, and/or attempting to consume the whole vast meal in a single sitting.*

- 7) **Use an open, easily maintainable, and adaptable software platform.** Today, software such as web interfaces, web dashboards, mobile apps, and secure, scalable hosting are all ubiquitous and easily outsourced. Software can easily be developed using standard components, or platform software such as Salesforce. The days of large software organisations creating overly complex projects using closed proprietary systems, should be a thing of the past. The important choices are:

- ✓ creating an open system (already discussed), and
- ✓ ensuring it is easy to maintain and adapt. (e.g. not being tied to a single supplier or expensive software licence agreement.)

This last point is often overlooked and must be factored into the project from inception as the costs of maintenance, support, and adaptation can often dwarf those of set-up in the longer term.

## Challenges & Opportunities for Government. (e.g. Payors & Regulators)

As the collection of real-world data and in particular 'Patient Reported Outcome Measures' (PROMS), becomes routine, payers (governments or insurers) will be looking to make good use of it. They already recognise that:

- they are paying for treatments that in many cases don't work – or have limited impact;
- that there is huge waste in healthcare - estimated at over one fifth of all health spending.

Currently, payers use simple financial agreements to pay for medical interventions. Going forward better data infrastructure will provide an era of risk sharing where Outcome Based Agreements (OBAs) will become the 'norm'. There is an increasing appetite for these in the US, where 22% of managed care organizations are already using such contracts (as of Jan 2019).

To date this has not materialised within Europe for a variety of reasons, although, Italy it appears has been making greater strides supported by new regulations adopted in 2015 that enforced the use of digital patient registries<sup>2</sup>.

We know that in the UK that big Pharma are beginning to implement their own OBA programmes and as the Italian experience shows, integrating better data into day-to-day healthcare will ultimately help drive better value.

## Conclusions

The potential of Integrated Digital Health is likely to bring benefits that are both radical and wide reaching:

- ✓ In the licensing of new drugs, it will dramatically improve market access through more equitable pricing & reimbursement discussions.
- ✓ For patients it will ultimately improve outcomes and their quality of life.
- ✓ For healthcare providers it will improve the quality of care they can provide.
- ✓ For Government and taxpayers (or insurers and policy holders) it will reduce waste and improve the 'value' of care as measured by Quality of Life (QoLs) divided by Costs.

**Building-in the routine collection of Patient Reported Outcomes Measures (PROMs) through an Integrated Digital Healthcare approach centred around people and patients in the community will make Outcome Based Agreements a reality and will usher in arguably one of the most transformative health advancements of the last decade.**

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<sup>2</sup> Xoxi, Entela, Italian Experience on Registries, March 2016