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Patient Centricity:
Data ownership & control

Introduction

The healthcare sector is ripe for digital transformation.

As a public service it is seldom out of the news, usually for all the wrong reasons. It is a sector that is constantly under pressure from seemingly intractable challenges. Lack of resources. Continually mounting workloads. Organisational complexity.

Meanwhile, expectations remain consistently high. After all, few services are as important to us as decent quality healthcare.

Better use of patient data offers the prospect of transformational change. Better engaged and informed patients. Huge cost savings and efficiency improvements. Truly personalised healthcare. A research revolution. Fresh innovation. Better outcomes.

Of course, to get to this promised land we must first clear several obvious hurdles. Patient data must be made interoperable – easily usable across different systems – while ensuring security and protecting the privacy of individuals.

The new EU General Data Protection Regulation (GDPR) and similar legislation in other countries is putting in place the regulatory structures that will help to meet such challenges.

Along with the ubiquity of mobile technology and low-cost computing power, the climate now is right to make Patient Centricity a reality that benefits health services and the people that use them.

The challenge

Populations are highly mobile. Patients have to navigate a complex health landscape, crossing between specialities, organisations, sectors, regions or even countries. However, while the patient might traverse the health ecosystem, their data tends not to follow them. Even when it does, the information is often incomplete, inaccurate or out of date.

The idea of putting the patient at the centre of healthcare provision is not necessarily new, with past attempts to design systems around the individual's needs. Such efforts have often tended to miss an important point, though – the need to allow information to flow more effectively. The typical patient's experience is of being in the centre of a web of activity over which they have little or no control, with their data passed around them in the healthcare system.

It means having to negotiate systems and services where there data is:

- Distributed, existing in many silos
- Difficult for patients themselves to access
- Even more difficult for them to share
- Not always available when they or their healthcare provider needs it
- Often obtained indirectly or only in part

In addition to this inherent complexity, the use of patient data will always run into the significant issues around security, privacy and consent. When consent is implied or assumed rather than explicit and informed, it adds further challenges to the effective use and sharing of this data.

Such difficulties lead to massive inefficiencies and stifle innovation, as well as having a negative impact on patients, care and outcomes.

This is a massively complex landscape for industry, too, with no clear points of access to data, little interoperability, and a varied set of standards combining to create an enormous technical and commercial challenge. The investment needed to even start providing solutions can sometimes be prohibitive.

Furthermore, with the incoming GDPR, Meaningful Use Stage 3 in the US and other emerging regulatory requirements around the world, the bar for sharing data is being set ever higher. A significant change is needed to the ways information is shared. Healthcare providers should look to the emerging Personal Data Ecosystem (PDE) for innovative models that allow greater sharing of data while simultaneously offering individuals more control and greater privacy.

Such models show how these twin goals don't have to be mutually exclusive, by making each of us the repository for our data. This is the essence of Patient Centricity.

The case for Patient Centricity

Health services have spent billions trying to join up this vast and complex landscape, mostly only succeeding with basic data flows. The idea that there could ever be a single, centralised, complete and accurate health record for each individual has always appeared beyond reach.

However, even amid such complexity there is one single point of integration which, regardless of location or healthcare service, will always be the same and that is the individual, the patient.

By simply doing one thing – giving all data back to the patient each time they interact with a healthcare service – would create a single, consistent record over time.

It would mean the patient has all their clinical encounters, test results, admissions, discharge summaries, even their X-rays and imaging scans.

A complete and accurate longitudinal care record would now exist in one place.

And when the individual has complete ownership and control of this single consolidated record they can start to share and use it in new ways.

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Key principles

While conceptually simple, making Patient Centricity a reality will involve overcoming some technical and, perhaps more significantly, ideological challenges.

However, a number of key principles show how achieving true Patient Centricity need not be a daunting prospect:

- **Freely and routinely give data back to the individual**
The individual must truly own and control their data. It must be free and given without the need to constantly apply for or request it.
- **Accepting the world is not perfect**
Make progress today and manage the imperfections rather than trying to perfect and fix everything before patients experience any benefits.
- **Agile and iterative**
Start small, establish foundations and build from there to enable patients and providers to experience benefits as early as possible.
- **Minimal change**
Work with existing systems and processes whether local or national. For example, many health providers may already have processes for giving data back to the individual.
- **Digital by default but provide choice**
The world will only become more digital, so it is important that data is given back to patients in an electronic and machine readable format. However, provision should also be made for those patients who would prefer their information printed or in an email.

One of the more immediately compelling aspects of Patient Centricity is that it doesn't require healthcare organisations to change existing record-keeping practices or processes. Certainly, in the early stages of a shift towards complete Patient Centricity, the majority of existing practices can continue as today and healthcare providers need only make one change, giving data back to the individual.

Spectrum of sharing

The sharing of data is usually at odds with maintaining privacy because an individual's personal data tends to be fragmented and distributed across multiple platforms, apps and accounts. Privacy is compromised when sharing data involves transferring it away from the individual's device or infrastructure.

With Patient Centricity, every individual owns and controls all their data including health records. If a person then has a means to safely and securely share data, several significant benefits become apparent:

- There is one place to go for complete and accurate data.
- Individuals can share data on their terms with explicit and informed consent.
- Industry can innovate directly around the individual, enabling of 'Me2B' business models.

When an individual has their data in their own device or infrastructure they can start to share or use more data and with greater privacy, and it also means service providers can move processing closer to them.

Of course, data can still be shared 'off device' in a more traditional manner, but with much greater transparency and control and, most importantly, explicit and informed consent.

This flexibility and control allows for a spectrum of sharing.

Commercial private sharing example

A health insurance company wants to keep its customers healthy so that they are less likely to make a claim. It wants to provide customers with an app that offers advice on living more healthily with incentives for achieving lifestyle goals. As well as accessing medical records, it would request data relating to your shopping, lifestyle and wearables. The company also wants to be able to use customer data to better evaluate risk when calculating premiums and to personalise its product offerings.

However, holding large amounts of customer data is a liability for the insurance company and is also a barrier to engagement for customers.

Patient Centricity would make it possible for the insurance company's app to access the customer's data and process it locally without it having to leave their device. Instead, the app returns just the output necessary to make a decision or provide a service.

The impact

The benefits of giving health data back to the individual are well documented, particularly when it comes to direct care and improving efficiency and outcomes.

Enabling Patient Centricity provides three headline benefits:

- **Whole patient picture – each individual has a complete, rich, longitudinal record and they become the single source for sharing this data.**
- **Maximum privacy and sharing – individuals get greater privacy and control while organisations get explicit and informed consent with the ability to minimise the costs and risks of compliance by processing data on the device.**
- **Build stronger relationships – transparency and the empowerment that comes with giving back data helps to establish trust with patients which, in turn, leads to greater sharing and value.**

These headline benefits lead to further advantages across the entire health landscape with a new model for patients, hospitals, doctors, research, industry and government:

- **Empower and engage patients – drive better outcomes and reduce costs for the health system.**
- **Efficient healthcare and communication – improve the quality and efficacy of healthcare services.**
- **Accelerate research – reduce barriers to research and improve the breadth and quality of data available to researchers.**
- **Catalyst for innovation – industry and healthcare providers can innovate around the individual, providing entirely new services.**
- **Government and society benefits – a population of healthier, happier people increases productivity and helps to generate greater national wealth.**

While one of the most compelling benefits for many organisations will be that Patient Centricity saves money, there are many other ways it can transform and improve healthcare and enable new developments that were not possible before.

Again, it is a simple concept that can give rise to these many, significant benefits – give data back to the patient.

Enabling Patient Centricity

Overview

History has taught us that health IT projects are often complex, requiring huge amounts of resources and organisational change with radical shifts in behaviours, cultures and processes.

Patient Centricity is a radically simpler approach requiring minimal change. To get started it requires only the commitment to give data back to the individual – nothing else has to change. Most organisations are capable of doing this today, even if only in very basic ways. Doing so lays the foundations for a journey towards true Patient Centricity. Each subsequent step is then a matter of making the return of data to the patient a routine process. As organisations progress along the Patient Centricity path, they are able to incrementally build on established, tried and tested mechanisms until such point all the data and medical notes are available.

Modern healthcare systems already support the ability to make data available through downloads and portals. However, a more efficient and effective way to do this is through APIs (application programming interface) for use by apps and services that the individual chooses.

Providing data via patient-facing APIs:

- **Gives the individual choice about what apps and services they use their data with.**
- **Enables healthcare providers to build an ecosystem of apps and services including portals.**
- **Removes the huge limitation of a single vendor or portal.**
- **Enables wider and more flexible innovation with industry.**

To get started requires only the commitment to give data back to the individual

The healthcare service provider retains control of what data is made available to whom and when. Patient-facing APIs give control back to the individual, enabling them to automatically get access to their data which they can store on their own personal devices or cloud storage.

This type of capability supports important regulations and legislation relating to data portability and the provision of APIs.

Where to start?

The idea of giving individuals their health records has been around for a long time and was probably first established in developing nations where there were no central mechanisms to store and hold physical records.

Digital attempts at something like a Patient Centricity approach have been tried with limited success, primarily because only recently has the technical capability existed for it to be possible in an automated way and at scale.

While some people might prefer to have their data returned to them in analogue form, the key to realising the full benefits of Patient Centricity is to be able to give data back to the individual in an electronic and machine readable format.

In many health economies, individuals will often have a GP (General Practitioner) or a relationship with a particular doctor who will hold their primary/summary record. Other organisations will often report back to this primary doctor even if only in summary form.

Patient Centricity should initially start small and establish the building blocks for data sharing with high value, low risk datasets that may well already be available to individuals such as encounters, vaccinations, medications, allergies and conditions. As an organisation's approach to Patient Centricity matures, the sharing of more complex or higher risk datasets can be iteratively enabled using the same processes and capabilities in an agile manner.

While portals and downloads can make data available to patients, APIs offer the most efficient and effective mechanism to share data and enable Patient Centricity.

Where an API isn't available today, existing capabilities can be exploited to enable Patient Centricity in the interim. However, APIs can be developed with ease and at low cost, especially where portal capabilities already exist.

From a process point of view, most organisations will already have the mechanisms in place to handle data requests by patients. These same processes require little or no modification to enable the individual to gain access to their data, especially where there are already mechanisms in place for gaining access to portals. It is imperative that organisations provide clear and simple

processes and openly publish their technology. This ensures individuals have the best chance of accessing their data and using it with the apps and services they want.

Conclusion

The case for Patient Centricity is clear and compelling. Giving individuals their health data offers the prospect of truly personalised healthcare that has until now been a prohibitively expensive aspiration for all but the wealthiest few.

It presents an opportunity for everyone to see and understand their own medical information, allowing them to consciously share it for more direct engagement with services.

At a stroke, this simplifies the vast complexity of disparate systems and administrative processes. The individual becomes the single source of accurate, up-to-date and comprehensive information about their health. They also benefit from greater privacy and control over how that information is used.

The healthcare industry benefits from enormous efficiency savings while delivering more personalised services. Patient Centricity reduces the liability associated with holding patient data, making compliance with data protection regulations more straightforward.

The potential advantages of this new model are profound and yet making it a reality requires minimal change to current systems.

The simple, but significant, shift to giving back health data would also fuel innovation, making possible new services and products designed around the patient's needs.

In essence, the Patient Centricity philosophy can be achieved through giving patients their health information in any format. However, technology offers the means to unlock its full potential. Digital records can be transferred, aggregated, stored and shared quickly, securely and at minimal cost.

The digital world we live in makes true Patient Centricity not just a possibility but a golden opportunity.