OpenOutcomes, open source, open standards?

What is openOutcomes?

openOutcomes is an open source, highly interoperable platform to collect, record and analyse patient reported outcomes (PROMs), initially for orthopaedic surgical procedures.

What is open source?

The term 'open source' refers to the licence under which the software is released. Our aim is to produce a publicly accessible solution to which users can contribute and share with each other.

What are open standards?

There are a number of open standards used throughout the NHS (HL7, FHIR, SNOMED CT, OpenEHR and IHE-XDS). Each standard serves its own purpose. We believe that the data created in Open Outcomes should be stored in an openEHR format. This format is used internationally to store clinical data which is not locked into one particular vendor or data store and can be further used for research purposes as and when that need arises. As a team we will build the clinical models used by openEHR, these will be shared and reviewed by our peers. By working in this way we can agree the models that can be used to facilitate interoperability for healthcare.

What will openOutcomes do?

openOutcomes will provide a comprehensive digital PROMs collection tool for clinicians, their administrators and for patients. Users will be able to collect, record and analyse patient reported outcome measures through standardised and validated outcome questionnaires.

Who is developing openOutcomes?

We have formed a committee with the Apperta Foundation, a clinically led not for profit organisation. Apperta is the Custodian of openOutcomes. They ensure that it remains an open platform, legally compliant, and manages the collection of processes, procedures and policy that support the members and govern the professional services partner networks. The committee will work with a range of developers to ensure the product is created and released open source.

Will openOutcomes integrate with our current EPR?

In theory, yes. As openOutcomes is built open source using an open standards (OpenEHR) approach, this makes that data at its core more interoperable. The level of integration will be determined by your EPR provider allowing us to integrate via OpenAPI's or FHIR API's. The NHS is now encouraging EPR providers to allow systems to interoperate more easily and to avoid data silos. This is the heart of the openOutcomes software i.e. an open platform that is highly interoperable with electronic records that is not tied down to any particular vendor (Vendor neutral).

How easily can openOutcomes be deployed in an NHS trust?

For our subscribers the software will easily be deployable as a software package ready to go. However, as with all digital implementation in the NHS there needs to be good support from trusts' digital committees, staff & other relevant stakeholders. Investment in hardware resources will also be needed to take full advantage of the software. openOutcomes will provide those trusts which have limited resources the means to implement a cost-effective digital PROMs solution.

What can openOutcomes can do for us?

How will openOutcomes improve patient PROMs?

Having effective and robust software to capture PROMs allows teams to analyse their data in real time to inform clinical practice. Our aim is for openOutcomes to have comprehensive analysis tools to review PROMs data at any time, providing patient level data for monitoring individual outcomes. Wider data analysis functions would facilitate quality improvement, audit and research work, and additionally provide individual consultant PROMS for revalidation and appraisal.

Which PROMs will openOutcomes record?

We have included most of the common orthopaedic PROMs used in the NHS. (Please see the Apperta website for current list.) Any additional - including non-orthopaedic - PROMs could readily be added by creating an archetype (information architecture) for any particular tool/questionnaire.

Can openOutcomes be used with an app?

The ultimate aim is to have a comprehensive platform available on a web browser initially and subsequently developed into a mobile app on smartphones and tablets for patients to directly interact with. Once the basic platform has been developed, however, third party app developers would be able to create customised apps which could feed in to it.

Is openOutcomes free?

No, we are asking subscribers to contribute £15,000 per year which gets them a fully functional PROMs software platform for unlimited use. Once developed, the code will be released as open source, so if others are prepared to wait long enough, the actual code would be free. Without sufficient subscribers this could be a very long time, and they would still need to employ someone to install and maintain the platform for them.

Do we need a commercial partner?

Not necessarily. Subscribers to openOutcomes will receive support for the installation and maintenance of the fully functional software, or local trusts' IT teams may be able to help with deployment. For non-subscribers and for full integration with your existing EPR commercial partners may help in deployment depending on local trusts' implementation strategies.

Why use openEHR standard for PROMs?

Many of the common validated orthopaedic questionnaires haven already been built into archetypes but others may be requested by users, or new ones may be developed in the future. As openOutcomes is designed in openEHR and is clinically and community driven, new questionnaires can be developed into archetypes and coded into the software more simply and speedily than by individual commercial suppliers. With this community approach PROMs questionnaires can be reused by others making its continuing development and use in clinical practice extremely quick and effective.

Can data be fed into national registries?

Yes, it is possible to integrate with any electronic platform and push data to registries, with appropriate permissions and consent. However, the commercial registry provider will need to agree to this.

Will the PROMs questionnaires be available in different languages?

PROMs could be made available in other languages as openEHR archetypes are designed to be multi-lingual, so adding translations and have them peer-reviewed is fairly simple. Some of the copyright owners of the scores put conditions in their licenses preventing translation without their consent and this would need to be checked.

Subscription Model?

How many subscribers?

A number of trusts have already subscribed between £5,000 and £10,000 each with the aim of starting the build. Realistically we now need 9 more subscribers (April 2021) to enable complete development with all desired additional functions.

How much does it cost?

We are asking subscribers to contribute £15,000 per year to allow the software to be built, maintained and continuously improved.

What does this get us?

An easily deployed comprehensive digital PROMs collection platform and the option of joining the clinician-led committee to shape the future road-map of the product.

How is this different to buying commercial software?

openOutcomes is designed by its users, i.e. clinicians and admin teams. It is based on open standards which means that as well as being open source, its data is stored in an OpenEHR Clinical data repository (CDR), a recognised international standard widely used in health and care. The software is designed to be interoperable with other electronic records and is not tied down to any particular vendor (vendor neutral). This allows other software developers familiar with OpenEHR data structures to easily integrate their software into the OpenEHR CDR allowing end users to choose the tools (apps and interfaces) that best suit their needs. Developers can focus on producing user friendly interfaces with clinical input on how the data is captured and stored; they can produce excellent functionality rather than spending time and money re-writing the questionnaires in their own data format.

Information Governance?

Where is the data held?

Users have the option of having the software and data on their trust's own servers or on a secure cloud server of their choice.

Who owns the data?

Legally the data "owner" is the 'data controller' who has a responsibility to maintain data quality and decide on access/sharing rules (e.g. the clinical organisation). Although clinical organisations are generally considered the 'data controllers', in practice, for proprietary systems the software supplier exerts a strong degree of control, since they 'own' the data structures used internally. With openEHR CDRs, this control becomes almost fully ceded to the clinical organisation, which decides which information models to use and can deploy them without any need to ask the CDR supplier. So initially at least, the 'data controller' will be almost wholly, if not completely, the clinical organisation'. Increasingly however, patients are seeking more control, particularly with regard to distribution of data about them and the Apperta approach supports this idea. Our hope is that at some point data will be co-produced and co-owned with a defined set of rights and responsibilities to maximise patient control without compromising the medical-legal trustfulness of the records.

Can the data be moved?

As the data is stored in an open, computable standardised (OpenEHR) structure, any software provider chosen by the user can develop software in OpenEHR. At the user's request, they can then plug in to the user's existing data to add it to their own platform with minimal cost associated with data migration.

Apperta?

Who are Apperta?

The Apperta Foundation is a clinician-led, not-for-profit company. Supported by NHS England, NHS Digital and others, they promote open systems and standards for digital health and social care. Apperta show how the delivery of health and social care can be transformed when data, information and knowledge in IT systems is open, shareable and computable.

More?

Apperta: **https://apperta.org/** **with links to** openOutcomes Apperta information **and** PDF

E-mail: info@Apperta.org   **or**   Angela.kingman@nhs.net

Twitter: @AppertaUK   @open_Outcomes

@Outcomes_PROMs   @KTheivendran