

openOutcomes and Patient Report Outcome Measures for MSK (and other conditions)

Overview

openOutcomes will be an industry leading electronic platform for the collection and use of Patient Reported Outcome Measures (PROMs). It will allow all community and secondary care providers to develop their own PROMs programmes. The data collected will support service improvement and provide rich evidence for those commissioning their services.

openOutcomes would expect to bring a range of benefits for organisations using the system including:

- Cost savings by reducing the administrative overhead of the PROMs recording process and reduction in the reliance on posting paper forms to patients
- Increased compliance for the completion of PROMs questionnaires due to the ability for patients to submit them via their mobile device or computer
- Advanced reporting allowing performance to be evaluated at clinician and population levels
- Access to structured data for patients, interventions and PROMs allowing correlations to be identified and used to improve care
- An ability to automatically submit PROMs data to national registries (where those registries allow and with appropriate consent and permissions). The requirement for which is likely to increase following the Cumberlege Report “First do no harm”.
- Providing the ability to connect PROMs data to other data sets (for example genomics) giving the ability to lead advanced research programmes with the potential to connect to Artificial Intelligence tools

The Problem

Clinicians have little objective evidence of their outcomes from treatments and benchmarking data is particularly lacking. Patient Reported Outcome Measures demonstrate the effect of treatment, or no treatment on patients. PROMs collection is resource intensive which either leads to Trusts not having a PROMs programme, or to Trusts committing considerable staff time and a variety of recording methods (e.g. paper, Excel, local databases). This means that data is not collected in sufficient quantity, nor in a standardised way.

With an established PROMs programme, data allows individual patient outcomes monitoring as well as evidence that the community and secondary care offers effective treatments with consistent outcomes (required by commissioners and Getting It Right First Time for example). Most interventions in healthcare have no measured outcomes in terms of impact on patients and although a wide variation in outcomes is expected, most outcomes from our interventions are not known.

The Government response to the report of the Independent Medicines and Medical Devices Safety published July 2021 states that “Patient reported measures such as Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) should become common currency in the assessment of the benefits and risks of current and new interventions” and that

"Every interaction the patient has with a health service provider should be captured once only and by one or other data subset, ideally in the electronic health record. The NHS number should be included to enable those subsets to be linked"

In a recent UK audit (“EMPROVE”) into orthopaedic secondary care PROMs practice, 38 NHS trusts submitted data across 9 regions in the UK. Eight trusts (21.1%) have a designated PROMs manager whilst in 18 (62.1%) consultants were responsible for collecting PROMs. Outside of registry collection (which is the vast majority of interventions) there was less reporting of PROMs (26%) with greater variation in the PROM collected and their collection intervals.

With openOutcomes, Robust methods of outcome data collection and analysis means that patients will receive a better level of care individually and collectively as organisations can benchmark. There are existing commercial electronic options available but these can cost each NHS organisation up to £50,000 p.a. and there is little opportunity to customise them to fit local practice. These options often have a significant degree of vendor lock-in with inability to extract the stored data in a useful format, and little or no interoperability with existing I.T systems.

As well as bespoke software to collect and analyse outcome data, some administrative staff time is required to run a PROMS programme. Employing staff dedicated to PROMs collection and use is likely to cost a minimum of £15,000 per 1,000 new patient procedures using paper and manual methods.

The Solution

Instead of using commercial software, we can do this collectively, reduce cost and deliver a best in class solution designed by its users. In partnership with experts, openOutcomes is a clinically led solution which will be open source and based on open standards. NHS service standard states that new solutions must: “Use and contribute to open standards, common components and patterns” and “Make new source code open”. openOutcomes will use openEHR to store all clinical data to maximise interoperability. We are anticipating using the EHRbase Clinical Data Repository (CDR) running in a recognised, secure cloud hosted environment such as UK Cloud. All data collected via the software will be held in an open computable format (openEHR) which will facilitate data analytics and will be designed to interoperate with other IT systems.

Besides data being transcribed into the system by staff if required, features include:

- Tablets or PC browser entry by the patients in clinic within the hospital’s intranet
- Web and smartphone / tablet entry via the internet
- Automatic prompts when post-operative responses are due
- Prompts when questionnaires have not been received
- Reporting module
- Ability to analyse data and view charts, graphs, and tables with a variety of queries possible. This will allow real time data to be available to clinicians and teams within hospitals.
- Data push into national registries (where these registries allow) – further development

Highlights

- openOutcomes is a collaborative project run by a team of public, private and not-for-profit organisations with a focus on delivering the best PROMs solution at a cost of less than a third of current commercial products
- openOutcomes is crowd funded by NHS organisations
- it is anticipated that usage of OpenOutcomes may save each organisation collecting PROMS £10,000 - £30,000 p.a. compared to commercial solutions which offers no integration with community and secondary care settings, or between providers.
- it is expected that OpenOutcomes will free up clinician time by providing instant access to PROMs data
- openOutcomes will gather anonymous patient data that can be analysed by big data tools to get insights into and therefore improve patient care parameters
- openOutcomes is designed by clinicians and PROMs experts from within the NHS at every stage
- Although highly secure the data is collected in an open format, meaning that organisations are able to get access to their data should they wish to utilize / integrate the data into other products in the future.

Keys to Success

openOutcomes is led by a clinical committee of subscribers, partnered by the Apperta Foundation which is a not for profit Community Interest Company supported by NHS England, NHS Digital and others. Apperta promotes open systems and standards for digital health and social care and will have overall responsibility for governance. It will also play a key role in requirements definition, system testing, clinical safety, and security/privacy governance. More information can be found at <https://apperta.org/openOutcomes/>

openOutcomes is developed under the same principles of the established openEyes project which is now implemented in NHS Scotland, NHS Wales and 6 NHS Trusts in England (<https://openeyes.apperta.org/>). The openOutcomes committee, which is led by Professor Mike Reed, Consultant Orthopaedic Surgeon at Northumbria Healthcare NHS Foundation Trust, ensures the requirements of the development are defined according to clinical need. Other members of the committee are orthopaedic consultants, an NHS PROMs Manager and a university reader in medical data.

The developer is a professional software development company based in Manchester with over 11 years of experience in producing mobile apps and software systems for a wide range of blue-chip private sector clients including EE, Mercedes-Benz, Aviva, O2, BBC, Channel 5, Next and many more. Their medical software team specialise in the development of modular solutions using open standards that can easily be integrated into existing IT infrastructure using technologies such as OpenEHR and FHIR. They will be responsible for the full-lifecycle development of the software and support during its trial with Northumbria Healthcare NHS Foundation Trust and then implementation in the other partner trusts. They are committed to the development of this project and have already completed approximately 25% of the development with further funding allowing them to accelerate this process.

Financial Highlights

OpenOutcomes development includes clinician's portal, middleware and patient facing app is and some development has already been undertaken to produce a demonstration product. Further development is effectively being crowd funded from different organisations, with pledges approximating £50k so far received. Organisations wishing to get involved and make a financial pledge should contact The Apperta Foundation by mailing info@apperta.org

OpenOutcomes ongoing costs for professional services to help support and maintain the solution are expected to be about £15k p.a. per NHS trust. This is an all-inclusive cost and would include:

- support for the OpenOutcomes product
- training on how to use OpenOutcomes
- upgrades containing bug fixes
- upgrades containing new features that had been developed
- upgrades for security purposes
- support for OpenEHR, likely provided by a third party specialist software company rather than the developers
- upgrades and maintenance for the OpenEHR CDR where appropriate
- hosting for both the CDR and OpenOutcomes
- all of the required security, safety and data protection certifications/audits

It is expected that the final source code of the application will reside with The Apperta Foundation CIC and be made freely available as open source software under license terms determined by Apperta. Throughout the project there will be a focus on modularisation and interface abstraction to make the code as easy to re-use as possible.

Upon completion, the developers intend to offer this commercial level support for openOutcomes along with professional integration services. There is a desire within their company to contribute to the community surrounding products such as openOutcomes and therefore it has been agreed that 25% of revenue in relation to openOutcomes will be used to fund further research and development of the OpenOutcomes product.

Each NHS organisation will need administration time to run a PROMS programme. Some organisations have this in place and many clinicians, particularly physiotherapists, keep PROMS scores on their patients, albeit in an uncoordinated and non-integrated way. This product is designed for use at all stages of the MSK pathway and can be used in community and secondary care settings.

Appendix/references

OpenOutcomes: <https://apperta.org/openOutcomes/>

OpenOutcomes FAQ:

<https://apperta.org/assets/openOutcomes%20Frequently%20Asked%20Questions.pdf>

Government response to the report of the Independent Medicines and Medical Devices Safety:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004573/government-response-to-the-report-of-the-immds-review.pdf

NHS service standard: <https://service-manual.nhs.uk/service-standard>

NHS Digital open standards: <https://service-manual.nhs.uk/service-standard/13-use-and-contribute-to-open-standards-common-components-and-patterns>

NHS Digital open source: <https://service-manual.nhs.uk/service-standard/12-make-new-source-code-open>

Open source in the NHS: <https://publicmoneypubliccode.org.uk/>

openEHR: https://openehr.org/about/what_is_openehr & video: <https://youtu.be/BUwGNXppdbw>

Getting It Right First Time information: <https://www.gettingitrightfirsttime.co.uk/>

Best Practice Tariffs:

https://improvement.nhs.uk/documents/484/Annex_DtD_Best_practice_tariffs.pdf