HQIP Case study:
Registry evaluation by data subjects through electronic survey

This submission demonstrates:

- Registry data subject survey co-design
- Benefits of electronic survey for high response rate
- Seeking user views for optimum system capability

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Cystic Fibrosis Trust
www.cysticfibrosis.org.uk/registry

Summary

The Cystic Fibrosis Trust (CFT) holds the UK Cystic Fibrosis (CF) Registry, which lists information around everyone in the UK with CF for audit, research and monitoring, a powerful tool to determine best care and treatments.

The CFT seeks to continually improve public reporting and harness new technology, to meet the needs of people with CF, their families, healthcare teams, researchers and the wider NHS. Therefore an electronic survey took place to gauge interest in, and the requirements of, the UK CF Registry, by people with CF and their parents/guardians.

Background

The needs of the CF community, and technology, have changed since the UK CF Registry moved to the CFT in 2007. Many enhancements have been made to the Registry since, to allow monitoring of new treatments and use Registry data to inform commissioning of CF services. Seeking to build upon the success of the Registry by harnessing new technology to develop it further, the CFT has an idea of what is technically possible, and what might be needed based on experience, the views of the CF community, and looking at what similar Registries are doing in the UK and internationally. CFT wishes to ensure the direction taken meets the needs of people with CF, their families, healthcare teams, researchers and the wider NHS. Reliant on the trust from people with CF who consent to their data being collected by the Registry, it is vital to maintain this moving forward by consulting and communicating with the people at the heart of the Registry. An electronic survey became part of that process, steering the Registry to an even brighter future, with communication across the CF community as the key driving force.

Aims

To develop an understanding of the current needs of the CF community through an electronic survey and use this knowledge to increase the impact of the data and analysis generated by the Registry.

Objectives

To carry out and publish the results of an electronic survey aimed at people with cystic fibrosis and their parents/guardians in the UK.

Primary

- Understand how to develop Registry reporting.
- Understand how to harness technology to increase ownership of and access to data by the CF community.

Secondary

- Understand engagement with and interest in the UK CF Registry.
- Raise awareness of the UK CF Registry.

Approach

The survey questions were co-designed with a person with CF, the Cystic Fibrosis Trust's Head of Patient and Public Involvement, and the Registry team. Leading or loaded questions were avoided, keeping them general and open-ended, and allowing participants to qualify their answers using free text. The survey was designed using www.surveymonkey.com.

A summary of the Registry was provided within the survey to ensure those without existing knowledge of the Registry could respond. The survey was open to people who consent to data being collected on the Registry: people with CF and their parents/ guardians. People were given two weeks to complete the survey, which was sent out using CFT's Customer Relationship Management system, Facebook, and Twitter.

Two reminders were sent via all of these channels half way through data collection, and then through social media the day before the deadline. After the deadline, the survey was closed and data was exported into Excel to be analysed for published extended and at a glance reports.

Challenges

- Agreeing the question remit and wording took longer than expected, but delays were minimised by being very clear from the outset what input was being requested and why any suggestions were not incorporated.
- When analysing the results it was clear that the question wording in some cases wasn't sufficiently clear to the parent/guardian group, as they did not appear to realise their response should relate to their child, not themselves. In the survey report we were open and honest about findings such as this that could be improved.
- Some of the feedback was critical of elements of the Registry. Whilst publishing these results in the public domain felt slightly uncomfortable it was agreed that this was best in terms of stimulating future improvements as well as maintaining a culture of openness and trust regarding the Registry.

Outcomes

Outcomes included:

- 848 survey responses.
- At a glance and extended version of the report published on time.
- Recommendations incorporated into the 2014 UK CF Registry data report:
  - Plain English used in both versions.
  - At a glance rather than extended summary version published as a supplement.

Conclusion

An electronic survey is an efficient and cost effective way of gathering the views of people with CF and their families, provided it is designed carefully. In addition to achieving such a high response rate and demonstrating engagement with the Registry, it was concluded from the survey findings, for improvement action, that:

- People with CF want access to as much detail as possible, and see it as CFT's responsibility to ensure it is understandable, rather than summarising and depriving users of detail.
- People with CF want access to their own data.
- People with CF are open to sharing data with external parties, including industry and clinical trials, provided the processes and outcomes are clear, with an opportunity to opt in.

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