

## **NUDGEATHON 2021 BRIEF 1 - Targeting risk aversion in data custodians: A Decision Support Tool**

### **THE PROBLEM:**

“Digital information is the bedrock of high quality healthcare” (Australian Digital Health Agency, 2018). For researchers to harness this, data access is crucial. However, current data access is bottlenecked by inconsistent and opaque processes, asymmetrical information, and risk aversion by data custodians (Adams, Allen & Flack, 2018).

In order to improve the efficiency of data provision we propose a Decision Support Tool (DST) which will be used throughout the application and approval process. This DST is aimed to reduce the cognitive overload and risk aversion of custodians through the use of default rules, simplification and positive framing. In doing so, the approval of data access requests will occur more often and become more consistent.

### **THE FRAMEWORK:**

Based on the recommendation of the Queensland Health (QH) Data and Application Custodianship digital policy, the proposed DST will be used by all stakeholders throughout all stages of the application and approval process (QH, 2019). It will take the form of an online portal where users will manage their data access applications or review their data access approvals.

Data access applications will begin by users answering a number of screening questions about the project in which they are requesting data. These questions will apply to all data access applications and include the project's purpose, the intended use of the data, the specific data fields requested, etc. During this time users will also be able to view a summary of key legislation (relevant to the application) which will inform the data custodian's decision. This information will be used by the DST to categorise each project into different risk levels based on the level of identifying information being requested or implicitly contained in the data sets.

**Low risk** categorisation would include requests for aggregated data, or large data sets containing no information which could be used by itself or in combination with another data set to identify an individual. Data that is within the remit of general practitioners, hospital executives and clinicians will fall within low-risk as it is crucial to their role.

**Medium risk** categorisation would include requests for data sets containing some level of identifying information which could be used by itself or in combination with another data set to identify an individual. Small data sets on rare diseases which contain some level of demographic information may fall within this category as they can be combined with other data sets to identify individuals. This category requires critical evaluation of the potential benefits and risks. Most cases will fall into this category.

**High risk** categorisation would include requests for data sets containing clearly identifying information, such as when researchers or industry partners wish to merge datasets based on full name, date of birth, etc.

### **THE SOLUTION:**

The proposed DST utilises these different risk categories to apply different nudges which will reduce the cognitive overload and risk aversion of data custodians.

#### **NUDGE 1: Default Rules**

Low risk cases pose insignificant costs and in the absence of the DST would be approved. High risk cases pose significant potential costs and in the absence of the DST would be referred to legal counsel. Both high and low risk cases consume time and cognitive resources which could be better used on medium risk cases where the weighing of potential benefits and costs is less trivial. As such, upon opening a high or low risk data access request, the DST will immediately notify the data custodian of the projects' risk category, and whether it should be manually approved or referred to legal counsel.

Default rules have been shown to be effective in the case of retirement savings accounts (Madrian & Shea, 2001) and organ donation programs (Davidai, Gilovich & Ross, 2012). In this context, data custodians must still ensure the project has been correctly classified as low risk by verifying the type of data requested, however this default rule should significantly reduce time and energy spent on high/low risk projects based on the collected metadata.

### **NUDGE 2: Simplification**

For medium risk cases, data custodians must critically analyse the potential benefits and costs of projects requesting potentially identifying information. This process contains an overwhelming amount of information, with no easy form of comparison. Simplification has been shown to reduce cognitive overload in the case of bill reminder messages which increase tax-paying behaviours (John & Blume., 2018). In order to simplify this process, the DST will use an algorithm which lists previous projects from most similar to least similar based on the metadata collected. It will also display whether that project was approved for access or denied. The purpose of this algorithm is to create a reference point for approvals based on previous projects. In doing so it draws attention to the differences between projects, so that the data custodians can focus on whether precedent applies to this project, and if not, why.

### **NUDGE 3: Positive Framing**

The potential costs of approving access to identifying data may overshadow the potential benefits which occur both with uncertainty and into the future. Positive framing may be used to alleviate this risk aversion. Patients are more likely to adopt risky medical treatment when it's presented in a positive frame (survival rate) instead of negative frame (mortality rate) (Peng et al., 2014). The DST utilises positive framing by having applicants complete a short benefit statement summarising the anticipated positive outcomes of the project. This benefit statement will be the most salient part of the data access request and may reduce data custodians' loss and risk aversion by taking attention away from potential risks.

### **STAKEHOLDER OUTCOMES:**

The proposed DST affects all stakeholders due to it being the only way data access applications and approvals are processed. **Data custodians** are most directly affected, since they interact with the DST tool most often. In order for the DST to succeed, data custodians must provide information concerning what data is available for request and what fields each data set will contain (e.g. data dictionaries). The DST should however save significant time and energy by centralising the information provided by data access requests.

**Clinicians** and **executives** will be positively affected by the DST, since their data access requests will usually be classified as low risks. The proposed DST supports the overarching aims of the Digital Health Strategic Vision for Queensland, such as "more systematic, high quality and safer care" (QH, 2017), since clinicians and executives should have easier access to data vital in clinical decision making or hospital management.

Similarly **researchers** and **industry partners** will be affected since their data access requests will usually be classified as medium or high risks. The more consistent and transparent decision making process of data custodians should lead to greater engagement with the DST, meaning the research and industry innovation should be positively affected.

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