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Studying Health and Illness Experience using Linked Data (SHIELD): Empowering customers to donate shopping data for chronic pain research

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Introduction & Background

Chronic pain is considered a priority in healthcare and a threat to well-being across the globe, it is thus crucial to accurately measure the national levels of pain conditions and their impacts on workplace productivity and well-being.

Chronic pain has traditionally been studied in isolation with either self-reported survey data or standalone shopping records. The former are limited in scale and can be marred by response biases, while the latter lack 'ground truths': what research teams can measure are usually the purchase patterns of pain relief products, but neither the severity nor types of pain conditions.

Objectives & Approach

Data donation tools offer a novel approach to study chronic pain by linking the two aspects and establish statistical relationships between medicine consumptions and the multiple facets of pain experience. In a survey, we asked participants (N = 953) to share their loyalty card data with us, which is made possible with the data portability tool provided by Tesco (i.e., the largest supermarket chain in the United Kingdom) as part of the General Data Protection Regulation (GDPR). Based on questions adopted from popular inventories used in health research (e.g., EQ5D Health States, ONS4 Well-being, WEMWBS scales), we also asked participants to report the details of their pain conditions, hours of employment, and both general and mental health states. This allowed us to associate chronic pain - both subjective and objective (i.e., reflected by medicine consumption) - with its economic and personal consequences. Data collection was conducted via research panel providers, thus should approximate national representativeness.

Relevance to Digital Footprints

This work links digital footprints data donated by individuals to self-reported survey data, also develops an infrastructure for these data to be collected and safely stored.

Conclusions & Implications

One key value of this project is to pioneer a measure of chronic pain that can be applied to transactional records that are much bigger in scale in future analytic works. Our research team has access to an array of different digital footprints data, including longitudinal transactional data provided by a major pharmacy chain (20 million customers and 429 million baskets). In order to utilise these data to associate them with regional workplace productivity measures and well-being data released by the Office for National Statistics, a metric must be defined to extract the prevalence of chronic pain from shopping data, which is informed by the patterns found by the data donation project.

