

Simplifying Consumer Access to the information from Patient Outcomes Registers

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Background

There is a growing recognition of the healthcare benefits of allowing and assisting patients and carers (often referred to in healthcare as “consumers”) to access patient “outcomes” data for their particular health issue and/or location or life-stage.

A significant number of “Outcomes registers” exist, some in the public domain, others maintained by charities, research bodies or healthcare providers. The quality of this data varies but all face similar issues in managing wider and more diverse access to the useful information that they contain.

Naturally, and quite correctly, access to many patient outcome registers is tightly restricted, as individual records may create identification and confidentiality issues. Even in cases where design features have “de-identified” the data, certain combinations of demographic or healthcare juxtapositions can create the ability for inadvertent or malicious re-identification. There may also be technical access overload concerns, in cases where the original design of the technological infrastructure supporting the register was based upon only allowing minimum access to accredited and vetted personnel.

Both privacy and technical access issues are real. But there is often a simple design approach that can minimise the problems, and thus enhance the facility for patients to access the outcomes information that they are seeking for “People like me”.

The key point is that individual patients do not need, or want, to access other people’s individual data, so **individual access to the detailed data is not required at all**, in order to satisfy the “People like me” requirement, if, rather than treating patients as researchers, a “paradigm “ extract dataset approach is adopted for this purpose.

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Accessing ABS census data

Economic and social analysts frequently need information for analysis, that is derived from the National Census, but obviously ABS does not make the full, over 15 million, household data records available for such analysis.

Instead, a series of Census extract datasets are made generally available, based around the most likely coteries of data required for analysis. E.g. the number of males and females working in specific ANZCO occupation groupings, or ANZSIC industry categories, extracted by Local Government Area (LGA) assists Councils and State Governments to structure economic policies and programs.

ABS also provides a “fee for service” special extract facility for more detailed or specific extracts for analysis, which is often accessed by economic researchers for statistical and economic analysis.

Patient outcomes registers are “Census” type datasets

Whilst the actual record structure design of patient outcomes registers varies, the questionnaires used to populate them suggest how they are likely to be organised, and thus their potential design similarity to a census structure. (Indeed, the very fact that many are “point in time” datasets reinforces this similarity).

Accordingly, it is highly likely that the preferred ABS approach to the provision of “Occupations like us”, and similar economic data, derived from the census raw data, offers a cost-effective and simpler methodology to adopt to achieve a similar outcome.

Such a methodology would avoid many of the potential issues created by broad access to the outcomes registers original data and tailor the data presentation to the needs of patients and carers.

Extract Size and complexity

Assuming that “Like” is normally satisfied by e.g. Age group; Location; Disease or healthcare issue severity; Treatment option, the number of variations to the extraction paradigm can easily be calculated, and changes or extensions to such extraction paradigms easily determined.

Age group	7 age groupings	(per Census extracts)
Location	20 + regions (plus summary)	(Australian Government uses 21 regional groupings)
Disease severity	Various standard scales, usually 1-10	(whatever measure is available from outcomes register data)
Treatment option	6 – 10 variants	(based upon standard groupings)

The likely paradigm variants, on this scenario, would therefore be $7 \times 25 \times 10 \times 10$ = around 17,500

By organising the data in a “sheet form” for (normally) the largest variant (Location), the extract data set sheet would, on this structure, only require 25 sheets, plus a summary sheet, each containing a maximum of 700 lines, (1400-2100 if gender is a desired inclusion), with a series of columns of characteristic groups of perhaps two to three indicators of importance to Patients, each with the usual three data elements, i.e. minimum and maximum responses (to create “range”), and median to demonstrate “midpoint” for “People like me”.

This is smaller than many standard spreadsheets commonly used for analysis.

“People Like Me” paradigm datasets - advantage over pass extracts to the primary register

1. Compact size often able to be held within a dedicated web-structure
2. Zero concerns about privacy and confidentiality
3. Minimised access requirement to the detailed patient outcomes register
4. Easily accessible for multiple views
5. Easily extendable should further paradigms be required (without impacting outcomes register design)
6. Tailored versions could also be developed for specific research projects
7. Standard extract datasets could be downloadable for external independent analysis (like ABS census extracts)
8. Refreshable periodically, under a controlled approach, from the primary dataset, to maintain currency, with a single data extract pass
9. “refresh” could also provide comparison to the previous versions to allow for change analysis.