Identifying people from refugee backgrounds: health data collection, storage and access

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Identifying people from refugee backgrounds (including asylum seekers) in data sets in Victoria is vital to understanding health outcomes and service usage patterns of these individuals and communities. Identification also enables services providers, planners and funders to measure the impact of service changes on this sub-group.

Over the last decade significant work has been conducted in a number of areas relevant to identification of people from refugee backgrounds in Victorian state-wide data sets:

- looking at the best data items to identify people from refugee backgrounds in data sets,
- identification of relevant data item in routinely collected state-wide data bases,
- extracting data, aggregating data, and analysing data to understand health outcomes and service usage patterns of refugee and asylum seekers, and
- identifying improvements in data systems to assist with surveillance of issues.

The *Refugee Status Report* (Paxton, Smith, Ko Win, Mulholland, & Hood, 2011) was the most significant piece of work in this area[1].

Currently there are at least 18 ascertainment projects in Victoria focusing on refugee backgrounds populations. A clear need was identified to bring these groups together to discuss an approach that is consistent in the collection of data (Paxton, 2014).

This note and subsequent recommendations draws on three recent stakeholder meetings:

- Bridging the Gap[2] hosted a meeting "to identify useful questions" to identify people from refugee background to trial in their three year research project in maternity and maternal and child health settings;
- the Victorian Refugee Health Network brought together key stakeholders working in the area to provide "clarity" around current data collection processes and projects and work towards a briefing paper for the sector, and

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[1] The *Refugee Status Report* is available here
https://www.eduweb.vic.gov.au/edulibrary/public/govrel/Policy/children/refugee-status-report.pdf
[2] More information about Bridging the Gap: Partners for change in refugee child and family health is available here http://www.mcri.edu.au/research/research-projects/bridging-the-gap/

- the Australian Bureau of Statistics (ABS) and Office of Multicultural Affairs and Citizenship (OMAC) forum showcased some of the population data tools as emphasised 'the need for data in light of recent policy developments in Victoria'.

Summary

Data is routinely collected and collated for various purposes:

- to fulfil funding requirements,
- to identify vulnerable populations for fee waiver and/or priority access,
- to inform clinical care (and allow for single collection of this information),
- to inform service level planning, to monitor trends in referrals and presenting issues, and
- to inform population and service level interventions.

Decision makers on data collection include:

- government departments,
- service providers (individuals, private practices and organisations), and
- software developers.

Identifying people from refugee backgrounds in datasets is often not possible because:

- the systems do not have the requisite data items,
- there is not the capacity to retrieve the data in a useful format and/or
- databases are not compatible.

The following data items have been identified for collection, on the basis of validity, ease of administration and consistency with ABS data collection:

- country of birth,
- year of arrival,
- need for interpreter, and
- preferred language.

A fifth data item 'refugee or asylum seeker on arrival in Australia' needs to be explored further across settings to inform application.

A more apparently straightforward question –" Are you a refugee or asylum seeker?", is asked in a number of settings in relation to identification of those who are eligible for fee waiver or priority access (eg. oral health services for priority access and hospitals for Medicare ineligible asylum seekers), however, there are a number of challenges in asking this question, most significantly that the status of someone who is seeking asylum may change over time and many people on humanitarian visas may not identify as 'being a refugee' once they are permanent residents in Australia.

What do we recommend?

Recommendations on how to progress include

1. Collect four minimum data items routinely in all health data sets:
   o country of birth,
   o year of arrival,
   o need for interpreter, and
   o preferred language.

   A fifth data item 'refugee/asylum seeker on arrival in Australia' to be tested across settings.

   Including databases that are developed and/or administered by:
   o Commonwealth Department of Health,
   o Victorian Department of Health, and
   o medical software developers for private practitioners (e.g.: General Practice).

2. Standard tools developed for referral between health providers include four minimum data items and fifth item subject to further refinement to ensure question is right.

3. Standardisation of data items and dictionaries (such as utilisation of the ABS data dictionary) between databases to allow data from different services and departments to be aggregated.[3]

4. Training to support data collection, entry, retrieval and analysis that focuses on attitudes, skills and knowledge: to improve data integrity and utilisation of data systems to inform planning.

5. Service providers, planners, policy maker, funding bodies and consumers have access to data as appropriate for their role:
   o disaggregated or aggregated;
   o identifiable, or de-identified;
   o on demand, in quarterly or annual reports.

Other related recommendations include:

6. Consideration be given to inclusion of 'interpreting service provided' in data collection, with provision to capture time charged by interpreting services. (i.e. a 20 minute appointment may be charged for 90 minutes of interpreting as a minimum).

7. Further development of administrative processes and support tools for staff to determine whether someone is an 'asylum seeker' or 'refugee' to determine priority access and/or fee charge/waiver.

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[3] Interpreter required is not in the ABS data dictionary rather Proficiency in Spoken English. The ABS data dictionary can be accessed here:
http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2901.0Main%20Features802011/$FILE/2011%20Census%20Dictionary%2027102011.pdf

Figure 1: Data flow in health services including considerations at the point of input, storage and extraction.

Identifying people from refugee backgrounds in data sets to inform service provision.

Input

Clinical data collection

Person enters service

Administrative data collections

Client clinical file (sometimes paper based)

Smaller # of items

Service database

Smaller # of items

Funding bodies database

Decision

Clinical service provision

Macro service planning

Research

Funding planning

Policy making

Population data from other sources

Considerations
What questions to ask?
How to ask the questions?
Consultation with communities.
Quality of collection and entry.
The number of items are not burdensome on consumer or staff member.
Training and resources for staff.

Collect four (?five) minimum data items
- Country of birth
- Year of arrival
- Need for interpreter
- Preferred language
- ?Refugee or asylum seeker on arrival in Australia

"Refugee" is not a good data item as difficult to define, people self identify in different ways. However, in some settings questions about whether someone is an "asylum seeker" or "refugee" are asked to determine priority access and/or fee charge/waver

Description:
Minimum data set collected and transferred to funding body, however services generally collect more data.

Considerations:
Collect once use multiple times.
The compatibility of databases: services such as community health often have multiple databases.
Privacy concerns: security of data, only those who require have access.
Maintain integrity of the data include four(?five) minimum data items.

Considerations
Access to the data is available in useful formats for different purposes.
Access to reports of four (?five) minimum data items.

Possibilities
Builds understanding of service access patterns and health outcomes.
Helps us to understand impact of service changes.

victorian refugee health network