Using real-world data to identify health inequalities

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Real-world data (RWD)

“Data relating to patient health or experience or care delivery collected outside the context of highly controlled clinical trials”

NICE (2022)

One type of RWD is routinely collected data i.e. ‘everyday’ clinical information recorded in a service.
RCSLT Online Outcome Tool (ROOT)

Developed to support SLT services to collect and analyse RWD including:

- demographic details
- diagnostic information using ICD-10 codes
- outcome information using Therapy Outcome Measure (TOM) (Enderby and John, 2015; 2019):

  - Impairment
  - Activity
  - Participation
  - Wellbeing
  - Carer Wellbeing

RCSLT

University of Essex
ROOT so far

82 services contributing data

100 services in implementation phase

10 years of data from some services

81,985 episodes of care recorded

RCSLT
University of Essex
How can ROOT be used?

- Define and demonstrate SLT role
- Influence service planning and drive improvement
- Complement the evidence-base
Explore potential for ROOT users to:

- gather high level information about service users for the purposes of identifying trends / themes.
- compare their caseload to their local population, in order to explore unmet need.
- identify unwarranted variation in outcomes between different groups of patients within their service.
1. Agreement of fields to add to ROOT and how to code for these fields
2. Period of data collection to test feasibility
3. Development of new ROOT reports and graphics and testing phase
4. Evaluation:
   - Interviews with pilot representatives
   - Questionnaire for other service SLTs

Plus preliminary interrogation of aggregated data by SLT staff
Agreed fields

- Patient **ethnicity**, using locally determined categories
- **Deprivation decile** from nation-specific index of multiple deprivation, using patient postcode at time of therapy
- Requirement for an **interpreter**
- **Language** profile (three agreed categories to identify use of language(s) other than or in addition to English/Welsh)
Agreement of fields – key challenges

- Differences between nations and organisations
- Ability to compare with other datasets
- Terminology, especially around languages
- Reservations about using postcode as indicator for deprivation
- Requirements of different services
Table A: Completed episodes of care with data recorded on ROOT for each of the pilot fields, as of 01.09.2023

<table>
<thead>
<tr>
<th>Pilot field</th>
<th>Completed episodes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>3711</td>
</tr>
<tr>
<td><em>Combined figure for three different ethnicity categories</em></td>
<td></td>
</tr>
<tr>
<td>Interpreter required</td>
<td>3586</td>
</tr>
<tr>
<td>Language</td>
<td>2608</td>
</tr>
<tr>
<td>Deprivation Decile</td>
<td>3243</td>
</tr>
<tr>
<td><em>Combined figure for three different indices of multiple deprivation</em></td>
<td></td>
</tr>
</tbody>
</table>
Data collection – pilot findings

- Often, but not always, information available in existing records
- Still some lack of confidence around asking patients directly about ethnicity and languages?
- Logistical issues around postcode searches for deprivation decile
Analysing data at service level

Graph A: ‘Widget’ showing ethnicity of patients

Graph B: Report showing comparison of outcomes, based on whether patients required an interpreter

- Key:
  - Down
  - Same
  - Up

- Impairment
  - Yes: 55.2% (E = 29)
  - No: 49.2% (E = 1,933)

- Activity
  - Yes: 37.9% (E = 29)
  - No: 49.8% (E = 1,933)

- Participation
  - Yes: 32.1% (E = 28)
  - No: 45.7% (E = 1,888)

- Wellbeing
  - Yes: 44.4% (E = 27)
  - No: 49.5% (E = 1,787)

- Carer Wellbeing
  - Yes: 55.6% (E = 9)
  - No: 53% (E = 247)

Legend:
- Not Recorded - 2 (4.3%)
- White - British (A) - 13 (27.7%)
- White - Any other White background (C) - 1 (2.1%)
- Asian or Asian British - Pakistani (J) - 6 (12.8%)
- Not known (99) - 25 (53.2%)
Potential for identifying inequality but:

- Need for more data
- Lack of time and confidence
- Challenges with obtaining local population data for comparison
Table B: Breakdown of language use across all services

<table>
<thead>
<tr>
<th>Language category</th>
<th>Number of complete episodes</th>
<th>% of total recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>English / Welsh only</td>
<td>2498</td>
<td>95.6%</td>
</tr>
<tr>
<td>English / Welsh and another language(s)</td>
<td>90</td>
<td>3.4%</td>
</tr>
<tr>
<td>Only language(s) other than English / Welsh</td>
<td>24</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

Scotland’s Census (2011) 92.6% only spoke English at home
Census England and Wales (2021) 91.1% English (or Welsh in Wales) as main language
### Table C: Improvement in TOMs, according to level of deprivation of patient’s address (Index of Multiple Deprivation, 2019)

<table>
<thead>
<tr>
<th>Number of episodes where patient expected to ‘improve’</th>
<th>Total</th>
<th>1 most deprived</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 least deprived</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1098</td>
<td>129 (11.7%)</td>
<td>90 (8.2%)</td>
<td>65 (5.9%)</td>
<td>102 (9.3%)</td>
<td>84 (7.7%)</td>
<td>132 (12.0%)</td>
<td>126 (11.5%)</td>
<td>107 (9.7%)</td>
<td>109 (9.9%)</td>
<td>154 (14.0%)</td>
</tr>
<tr>
<td>Proportion resulting in improvement in one or more domains</td>
<td>85.4%</td>
<td>85.4%</td>
<td>88.4%</td>
<td>91.1%</td>
<td>81.5%</td>
<td>78.6%</td>
<td>84.8%</td>
<td>85.7%</td>
<td>85.0%</td>
<td>88.1%</td>
<td>85.1%</td>
</tr>
</tbody>
</table>

No patients in this group were identified allocated to the category ‘no fixed address’.
Conclusions

- Routine data collection has the potential to help explore inequity at a service and profession level
- Clinicians need time for data analysis and to develop knowledge and skills
- Issue is complex and often health inequalities are multifaceted
- Data is just one part of the picture.
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For more information on anything discussed, contact root@rcslt.org
References


Resources – ROOT

ROOT homepage including details of ‘drop in’ sessions
https://www.rcslt-root.org/Welcome

More information about ROOT

Register for ROOT
https://www.rcslt-root.org/Public/Register

Making data count videos
https://www.rcslt-root.org/Content/making-data-count-
Resources – health inequalities

Health inequalities guidance

Health inequalities resources, including:
  ○ Health inequalities audit tool
  ○ Using data to help address health inequalities
  ○ Health inequality indicator worksheet
  ○ Finding data about your local population
https://www.rcslt.org/learning/diversity-inclusion-and-anti-racism/health-inequalities/resources

Bilingualism guidance
https://www.rcslt.org/members/clinical-guidance/bilingualism/bilingualism-guidance/