Integrating rehabilitation information in Health Information Systems

Neville Calleja, MoH Malta
What is a health information system?

- eHealth system?
- hospital records?
- health promotion helpline?
What is a health information system?

The health information system provides the underpinnings for decision-making and has four key functions: **data generation, compilation, analysis and synthesis**, and **communication and use**.

The health information system collects data from the health sector and other relevant sectors, analyses the data and ensures their overall **quality, relevance and timeliness**, and converts data into information for health-related decision-making.
What is a health indicator?
What are (health) indicators?

“A concise definition of a concept meant to provide maximal information on an area of interest”

Kramers, 2005

Health indicators describe a particular aspect of health or health system.

Tell us something about an area of interest for (policy) action
- could lead to a concrete policy target e.g. reduce the percentage of smokers to less than 20%

Do this in a maximally efficient way ...
Do this in a maximally efficient way ...

- provide the simplest possible numerical presentation
- calculated from basic data
- basic data likely to remain available (sustainability)
- give a robust view of the situation

  e.g. Life expectancy as a measure for the overall age-specific mortality
  Healthy life expectancy as a measure of health in the population
  Rehabilitation bed capacity per unit population as an measure of potential output
What makes a good indicator?

Valid
Reliable
Relevant
Actionable
Internationally feasible
Internationally comparable
What indicators are NOT?

... A perfect and complete illustration (they only INDICATE)

... To be used as a final measure

... Free from any risk of manipulation
Data quality

- Policy makers have access to data required at the level required
- Data collection method in line with inter/national standards & recommendations
- Ability to meet all reporting requirements of international organisations of which MS is member/collaborator
- Adequate timeliness
- Adequate periodicity which meets the needs of policy makers
Metadata: data about the data

E.g. Maternal mortality rate

Metadata

The title
Maternal mortality rate = 50 deaths per 100,000 live births

How the indicator is defined
The number of maternal deaths per 100,000 livebirths in the same year

The data
The numbers that are fed into it
2 maternal deaths of children in a community where there have been 3963 live births
Donabedian approach
REHABILITATION INDICATOR MENU

A tool accompanying the Framework for Rehabilitation Monitoring and Evaluation (FRAME)
## Rehabilitation indicators

<table>
<thead>
<tr>
<th>Input &amp; processes</th>
<th>Output</th>
<th>Outcomes</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Governance</td>
<td>Services</td>
<td>• Coverage</td>
<td>Population functioning</td>
</tr>
<tr>
<td>• Financing</td>
<td></td>
<td>• Utilisation</td>
<td></td>
</tr>
<tr>
<td>• Workforce</td>
<td></td>
<td>• Effectiveness, <em>ie individual change in functioning</em></td>
<td></td>
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<tr>
<td>• Information systems</td>
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## Core indicators

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</tr>
</thead>
<tbody>
<tr>
<td>• Integration in health plan</td>
<td>• Tertiary rehab</td>
<td>• Multidisciplinary rehab for complex needs patient</td>
<td></td>
</tr>
<tr>
<td>• Financing</td>
<td>• Rehab bed density</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Personnel Density</td>
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</tbody>
</table>
Other national indicator needs ...

Mainly for:

- Health care standards monitoring
- Health care commissioning
Other national indicator needs ...

- Patient satisfaction
- Recommendation by patients
- Privacy
- Approach
- Physical accessibility
- Treatment plan and treatment goals
- Information for patients
- Complications (e.g., ulcers, falls)

- Condition specific standardized patient outcomes
- Percentage discharged home
- Waiting time to access service
- Cooperation within treatment team, and with patient organisations
- Accreditation
Ministerial needs …

Hello, Neville?

How much of XYZ do we have here?

I need the figure NOW!
Basic principles

- Having a legal framework eases secondary use of data.
- No data privacy issues exist around aggregate figures.
- Empowerment, trust and ownership amongst your stakeholders.
- Check your work by establishing concordance with external sources.
- While there is a preference for some data sources over others, you may have to adapt to your circumstances. Typically, you can safely assume that official sources are better than others.
Plan

a) Negotiate timeline with the stakeholder requesting information.

b) Best estimates of information can be obtained by linkage of registries and administrative data.

- Identify and define the denominator population.

- Identify administrative databases that could be linked to denominator population.
Execute linkage

c) Speak to stakeholders whenever possible.

d) Liaise with the database managers.

e) Obtain the required regulatory clearance.

f) Analyse the data
   – Obtain and clean
   – Linking datasets can be simple
g) In the absence of administrative databases, use survey data or any other aggregate figures from reputable sources.

h) It is imperative to use age-gender specific rates when the required estimates involve projections into the future.
Cross-validation

i) Check your estimates against any other that you may come across in your search.

j) Ask stakeholders for feedback on your estimates.

k) Report your findings in a concise, easy to read report.
The European Health Information Initiative is committed to improving the evidence on which policy is based.
European Health Information Initiative (EHII)

- Provides overarching coordination & guidance for health information activities WHO Europe;
- Multi-partner network;
- 12 Steering Group meetings held to date.
Current situation of health reporting in Europe

European Health Information Initiative

Networks
Communication
Strategy
Access
Capacity Building
Measurement

World Health Organization
Regional Office for Europe
The future: Integration of health information

Interoperability
Ability to exchange and make use of information

Harmonization
Definition, classification and interpretation of data indicators
1. **Strengthening health information systems**, harmonizing health indicators and establishing an integrated health information system for the European Region;

2. **Establishing and promoting health research systems** to support the setting of public health priorities;

3. **Increasing country capacities** for the development of evidence-informed policies (*knowledge translation*);

4. **Mainstreaming the use of evidence, information and research** in the implementation of Health 2020 and other major regional policy frameworks.

Adopted by 53 Member States through resolution

Concrete actions for Member States and WHO
EHII participants: 40
... and growing

Austria
Belarus
Belgium
Croatia
Czechia
Finland
Georgia
Germany
Greece
Iceland
Italy
Kazakhstan
Kyrgyzstan
Latvia
Lithuania
Malta
Netherlands
Poland
Portugal
Republic of Moldova
Romania
Russian Federation
Slovak Republic
Slovenia
Sweden
Switzerland
TfYR Macedonia
Turkey
Ukraine
United Kingdom
Annemiek van Bolhuis: Under the umbrella of the EHII
New themes added (AMR, child health)
gateway.euro.who.int
European health

- Flagship corporate publication;
- Every 3 years;
- Reporting on implementation of Health 2020 (baseline 2010).

Having crossed the half-way point of the implementation period of Health 2020, the 2018 report reflects on the effect and any aspects that may be unfinished by 2020 and beyond.
Disseminating health information: EURO public health journal

- Aimed at dissemination of good practices and successful implementation of evidence-informed policies;
- Bi-lingual (English/Russian);
- Quarterly publication;
- Theme-based;
- Peer reviewed.

Special issue on health information March 2019

Special issue on burden of disease December 2019
Health Evidence Network: WHO Europe’s evidence synthesis report series

Summarizes the best available evidence for decision-making;

Peer-reviewed, professionally written responses that are relevant, ready-to-use and evidence-informed;

An official WHO source for evidence – now listed in PubMed;

82 reports published to date – more to come;

Received ‘highly commended’ in BMA Book Awards 2017.

WHO's response in facilitating research use

69 synthesis reports published to-date – and more to come
REGIONAL COMMITTEE FOR EUROPE 65th SESSION
Copenhagen, Denmark, 12-15 September 2016

Action plan to strengthen the use of evidence, information and research for policy-making in the WHO European Region

Working document

World Health Organization
Regional Office for Europe
Autumn School for health information and evidence for policy-making honours its very first supporter

12-02-2019

WHO has recognized the contribution of Professor André van der Zande, former Director-General of the Dutch National Institute of Public Health and the Environment (RIVM) for his founding role in establishing the European Health Information Initiative (EHII) and the Autumn school for health information and evidence for policy. The letter of appreciation from Dr Zsuzsanna Jakab, WHO Regional Director for Europe was presented at the occasion of the 6th Autumn School held in The Hague, the Netherlands on 29 January – 1 February 2019.

Dr Claudia Stein, Director of the Division of Information, Evidence, Research and Innovation, WHO, praised Professor van der Zande saying that neither the EHII nor the Autumn School would exist today without the commitment and support of the RIVM and Professor van der Zande in particular. “None of us would be here today without you, Professor van der Zande, and we thank you from the bottom of our hearts for your leadership, support and commitment to enhance health information in the whole European Region”.

Contributing to better use of health and evidence in policy-making

The Autumn School focuses on equipping participants with practical knowledge and skills. “I learned about tools and good practice that can be used to bring health information and evidence closer to policy-making,” said Dr Sigríður Haraldsdóttir, Head of the Division of Health Information at the Directorate of Health in Reykjavik, Iceland, echoing the sentiments of many of the participants who took part in the Autumn School “I am excited and encouraged by this opportunity to gain more knowledge and learn from the experience of other countries and from WHO. I am convinced that what I have learned and will take home with me can contribute significantly to strengthening the Icelandic health information system. Participating in the autumn school was time well spent” she added.
## Health Information Networks under the EHII

<table>
<thead>
<tr>
<th>Name of Health Information Network</th>
<th>Configuration</th>
<th>Coordination</th>
<th>Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small Countries</td>
<td>Geo-political</td>
<td>WHO/MS</td>
<td>8</td>
</tr>
<tr>
<td>Commonwealth of Independent States</td>
<td>Geo-political</td>
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<td>8</td>
</tr>
<tr>
<td>CARINFONET (Central Asian Republics)</td>
<td>Geo-political</td>
<td>WHO</td>
<td>5</td>
</tr>
<tr>
<td>SEEHN</td>
<td>Geo-political</td>
<td>MS</td>
<td>9</td>
</tr>
<tr>
<td>European Burden of Disease</td>
<td>Theme-based</td>
<td>WHO/MS</td>
<td>14</td>
</tr>
<tr>
<td>European Health Research</td>
<td>Theme-based</td>
<td>WHO</td>
<td>6</td>
</tr>
<tr>
<td>Health Literacy Measurement</td>
<td>Theme-based</td>
<td>MS</td>
<td>20</td>
</tr>
<tr>
<td>Evidence-informed policy</td>
<td>Theme-based</td>
<td>WHO</td>
<td>21</td>
</tr>
</tbody>
</table>

Networks report to the Steering Groups of the EHII

Chairs are all members of the EHII
In conclusion...

“Ultimately, the secret of quality is love.
...... If you have love, you can then work backward to monitor and improve the system”.

Avedis Donabedian