Information systems to support child health and wellbeing

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Child health and wellbeing

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RICHE

Child?

Well-being and Quality of life

Measuring

Using
BRIDGE Health aims
to create a blueprint for a European health information system (EU HIS) and infrastructure;
to evaluate different structural and institutional options including a comprehensive European Research Infrastructure Consortium (ERIC) in health information; and
to prepare the transition towards a sustainable and integrated EU HIS for both public health and research purposes.
Bridge Health

... working towards a European health information and data generation network covering major European health policy areas.
Potential of Bridge Health

Sustainability

Improving health information for Europe

**Major challenges**

- Diversity of health services and health information structures
- Fragmentation in databases and registries
- Health information inequalities
- Lack of sustainability of health information structures

**Capacity for EU health information strategy**

- Knowledge management
- Health information priorities for MSs and EU
- Key determinants of ill-health and health inequality in the EU
- Enhance information on regional variations and inequalities
- Better information on healthcare quality and outcomes
- EU health system performance assessment framework

**Key impact on policy and health systems**

- Efficient resource allocation
- Better scientific evidence for policy
- Improved comparability
- More transparency and better targeting
- Reduced health information gaps across EU and MS
Bridge Health

We are Work Package 7 - looking at reproductive, maternal, child, and adolescent health

Our goal is very modest, to figure out how to measure the well-being of children across Europe
We draw, heavily, on four earlier EU projects
CHILD – child health indicators
RICHE – priorities for child health research till 2025
EURO-PERISTAT – maternal, fetal, and newborn health
CHICOS – coordinating mother/child cohort studies across Europe
Everyone uses different definitions of children.
In particular, there is a huge discrepancy between how health, education, and labour markets, view children

We have decided to go from conception to 24

Infant/child/adolescent/young adult

This aligns with WHO’s latest work, but cuts across many other data collection exercises, which often stop at 15, 16, 18 or 19.
Quality of life and well-being

Children for Health - Sharing Knowledge Saving Lives

100 messages to learn & share

DCU
Quality of life and well-being

We take a developmental perspective
Desired outcomes depend on age, but are geared towards achieving desired social outcomes
We cover both what is available to children and what they can do

School readiness at 5
Access to safe play area at home
Access to good quality technical education at 16
Not in Education Employment or Training at 19
Living independently of family at 24
Quality of life and well-being

There are hundreds of possible indicators
(See http://www.childhealthresearch.eu/ under Indicators)
Few are widely available
Almost none are available at local level, but this is where key decisions affecting the lives of children and young adults are often made
This is a problem
What’s the problem

Children are relatively invisible
They hide inside data collection across other social and biological structures, families, mothers, schools, healthcare, social care

Adults are usually more directly visible, and usually better documented

Many millions of children fall through the cracks

- Irish Travellers, Roma, migrants (legal and illegal)
- Children with parents who are not coping
Why does this matter?

Children are ‘all our futures’

We know that early life experiences, from conception onwards, can profoundly affect later life outcomes

This is really kind of obvious

We need to know where, and to whom, to deliver supports

We need to know if those supports are working or not

We need to know this at the right level to support decisions

‘What gets measured, gets managed’
Measuring

Not easy, but not impossible either

OECD, EUROSTAT, WHO, and UNICEF all have lots of usable measures at national level, with tools to facilitate international comparisons

The Innocenti research centre, part of UNICEF, has a series of detailed reports on child well-being in developed countries available at https://www.unicef-irc.org/

Most countries have a few – Ireland is ahead of the pack with the 2014 report ‘Better outcomes, brighter futures’
Measuring – what do we need?

Listen to children, adolescents and young people
Cross-disciplinary
Use all sources of data
Usable geography
Enrolling hard-to-reach children
Listen to the users

None of us really knows how best to measure the quality of life and well-being of children and young adults

We all have our own ideas, framed by our disciplines

Try asking

The results are always interesting, and may be more relevant than gazing into your own hearts
Cross disciplinary

Education
Employment
Social welfare
Health
Justice
Child protection
Housing
Use all sources of data

We often need to combine several sources of data

Routine data
Surveillance systems
Cohort studies
One-off research studies
One-off surveys

This is much easier to do if you use data standards
Usable geography

Stop messing – use census small areas
Hard to reach children

Really poor outcomes are very disproportionately found amongst the hardest to reach children
Not measuring them does not improve their outcomes
Put in the resources, monitor the completeness of ascertainment, do the work
Using

There is a culture of collecting data and then sitting on it. Sitting on data does not hatch it, instead it goes off. If you want good data – get it out there. Modern ICT makes this relatively easy, but Ireland is very bad at it. Speaking personally, if I never again have to extract a table from a PDF file, or a website, for further analysis I will be very happy.
Using it

We also need a culture change

It is far too common to see policy proposals, service reviews, and other documents, whether local, regional, and national, unburdened by any trace of real data, or analysis

This ought to be bad for your career, but middle and senior managers, journalists, politicians, and the Irish people, tolerate it all the time

Names are omitted to spare the guilty
Conclusion

We can measure child health – but only if we want to

We need to view ‘childhood’ as a continuum from birth to early adult life

This is an EU wide problem, and if anything, we are better than average

However, the average is woeful, so there are no grounds for complacency

We can disseminate information very easily, but we need to shift out culture towards data informed decision making