CORC
Child Outcomes Research Consortium

Flawed, uncertain, proximate and sparse (FUPS) data

Introduction

Researchers, clinicians and other mental health professionals hope that looking closely at large datasets can improve the quality of mental health services. In particular, it is hoped that routinely collected data can be used to establish benchmarks and help with evaluation.

However, such data are frequently flawed, uncertain, proximate and sparse (FUPS) data. They are:

- **Flawed**, due to missing or erroneously recorded data
- **Uncertain**, due to differences in how data items are rated and/or variation in case mix
- **Proximate**, in that they are always a proxy for an indication of the impact of the service provided
- **Sparse**, in that even within complete datasets the low volume of cases within a given subgroup often limits the applicability of statistical inference.

Some would argue that, given its poor quality, these data are not safe to use.

CORC's view

CORC believes that routinely collected outcome and experience data in child mental health are likely to remain flawed, uncertain, proximate and sparse for some time – arguably long enough to warrant coining the acronym 'FUPS'.

Given this, CORC believes that we need to find the best ways to use these data. Consideration of such data can be a spur to better quality data collection, and we can also use FUPS data to have more informed debates about what outcomes can be achieved by those seeking help from child mental health services.

CORC is aware that reporting on data where there are questions about the quality, and a high degree of missing data, is likely to be criticised. Respected researchers and others might argue that it is inappropriate to report findings as they may lead to fallacious conclusions based on flawed data and be used for unhelpful ends. There is much to support such an argument. However, CORC believes that analysis and sharing of such data is useful intelligence which can inform dialogue amongst key stakeholders, and is vital to advancing the field.

In order to support the best use of such FUPS data, we have followed best practice principles suggested in relation to the use of FUPS data. These principles, along with the acronym itself, were developed by Professor Miranda Wolpert, Director of CORC, in collaboration with Professor Martin Utley of University College London (UCL).

CORC recommendations

Reporting on FUPS data

As data analysts of FUPS data, organisations and individuals should strive to:

- help build a conversation around the data, rather than providing definitive answers
- provide accessible descriptive analyses first and foremost, and only undertake statistical tests where there is a clear reason to do so
- make explicit where cases have been removed from analysis due to issues of data completeness or quality
- stress that analysis may be limited, may not account for subtle clinical points and may contain mistakes
- respect and abide by agreed processes
- avoid 'black boxes'; for example, complex statistics on very limited data.

When presenting data, organisations and individuals should strive to:

- ensure the way that data is presented conveys any limitations to the interpretation of data, such as small volumes of cases, rare events and the intrinsically partial nature of any risk adjustment
- use precise and neutral language; for example, state that axis labels are factual (what was measured) rather than interpretive (performance or quality of care)
- avoid terms such as 'significance' or 'performance data' when referring to comparisons between groups
- provide full and precise definitions for metrics used in all cases
- include in displays and reports the raw numbers that analyses are based on, not just percentages and ratios in isolation.

Considering FUPS data

CORC recommends that FUPS data are used to inform facilitated stakeholder discussions involving practitioners, funders, service users, policy makers and others.

It is recommended that the facilitator of such conversations should, first of all:

- determine which groups are best brought together in which combinations, e.g. commissioners of services, service users, members of the public, practitioners, policy makers and researchers
- set clear ground rules for conversations (e.g. no point scoring, atmosphere of general interest, welcome critical thinking, focus on possible next steps and options that can aid best practice) with an agreed process for making a decision; however imperfect that process is
- ensure those considering the data have time to reflect and absorb the information.

The facilitator should then seek to help those present to:

- challenge their own and colleagues' confirm confirmatory biases
- maintain curiosity
- apply the same standards of scrutiny to analytic findings that support prior beliefs as to analytic findings that are uncomfortable or not wished for
- consider if any actions need to be taken in terms of quality assurance
- consider possible initiatives that, even if not definitively indicated, may do more good than harm
- challenge the assumption that change is always more risky than status quo
- help ensure adherence to agreed rules of engagement.

Concluding remarks

CORC argues that if FUPS data are to act as a form of intelligence to support thinking and decision-making, and as a spur to improved data collection, it is essential to start to examine what data we have as well as to argue for improved data – to walk the fine line between scientific rigour and scientific rigor mortis.

It is, of course, important to call for more and better data collection and higher quality data. However, it is only through examination of such FUPS data that can we start to have more informed debates about what outcomes should be expected to be achieved by those seeking help from child mental health services.

Further reading

- Coulter, A., Locock L., Ziebland S., & Calabrese, J. (2014). Collecting data on patient experience is not enough: they must be used to improve care. BMJ 348: g2225
- Keogh, B. (2013, 16 July). Review into the quality of care and treatment provided by 14 hospital trusts in England: Overview report. Retrieved from http://www.nhs.uk/NHSEngland/bruce-keoghreview/Documents/outcomes/keogh-review-finalreport.pdf
- Lilford, R., Mohammed, M.A., Spiegelhalter, D., & Thomson, R. (2004). Use and misuse of process and outcome data in managing performance of acute medical care: avoiding institutional stigma, The Lancet, Volume 363 (9415), 1147–1154.
- Wolpert M, Deighton J, De Francesco D, Martin P, Fonagy P, Ford T. (2014). From 'reckless' to 'mindful' in the use of outcome data to inform service-level performance management: perspectives from child mental health. BMJ Quality & Safety. 23(4), 272–6.