



Reporting and commenting on metabolic results

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Outline

- | Why is reporting important?
- | What are we trying to achieve?
- | Some features of good practice
- | Some points to bear in mind

Why is reporting so important?

- | It answers a question posed by the requesting clinician
- | It acts as a permanent record as part of the patients medical record
- | It can be used in future litigation
- | It is a serious potential cause of confusion
- | It is used to judge the quality of the service by users

What questions are we trying to achieve when reporting?

- | Is this normal?
- | Does the child have a primary metabolic disorder?
- | Is there useful information which may help monitor or modify treatment of patients with an established diagnosis?
- | Are there interesting features in this sample which may be clinically relevant?

What are the features of a good report?

- | It is clear, easy to read and unambiguous
- | It separates fact from conjecture ie findings from comment
- | It contains all necessary information and NO unnecessary information
- | It should be suitable for the target audience
- | It answers the question and is clear about the next steps if needed
- | It is as short as possible

Good practice (Normal)

- I It should unambiguously report “normal findings” without excess information.

eg No abnormality detected

No apparent evidence of a primary organic acid disorder

No significant biochemical abnormality detected

No significant abnormality

No apparent abnormality

No diagnostic abnormality detected

No specific abnormality detected

Normal

Good practice (Diagnostic abnormal)

- I Analytical findings
Key metabolites, degree of increase, method used (+ anything expected but not actually present)
- I Interpretation and conclusions
Likely diagnosis with some expression about the degree of certainty
- I Need for further confirmatory or other associated testing
Details of the samples needed and the degree of urgency in some cases
- I Need for testing of other family members
Details of the samples needed and the degree of urgency in some cases
- I (Need for urgent intervention)
- I Confirmation that the results have been telephoned if appropriate

Good practice (other findings)

- | Report only if clinically important
- | Is it answering the question being asked?
- | Will it affect management?

eg 2y male, FTT:

ketonuria + modest secondary DCA

paracetamol

aspartame

unidentified drug metabolites

- | Any further investigations – repeat samples with date for future samples if appropriate

Points to bear in mind

- | There is no obvious “right way” otherwise we would all be doing it
- | There are many “wrong ways” and few have been left unexplored
- | The reports are very largely subjective
- | The reporting systems have evolved in less than purpose built LIM systems with many artificial constraints AND some additional ease of use

Points to bear in mind

- | Reports are primarily written by “techi” people with relatively poor written skills
- | There is no formal training in report writing
- | Reports are primarily read by people who know almost nothing about inherited metabolic disease and whose first language may not be that in which the report is written
- | There is no agreed standardisation and no available EQA or IQC
- | There is almost no feedback and very few user audits related to content
- | Reports are often subsequently paraphrased to be entered into other LIM systems or to be used in discharge summaries or referral letters
- | They are used as a basis for treatment and occasionally litigation

A way forward

- | An exercise to evaluate current practice – collect examples
- | Agree and establish standards in liaison with users
- | Issue guidelines
- | Audit against standards
- | Regular re-audit and report