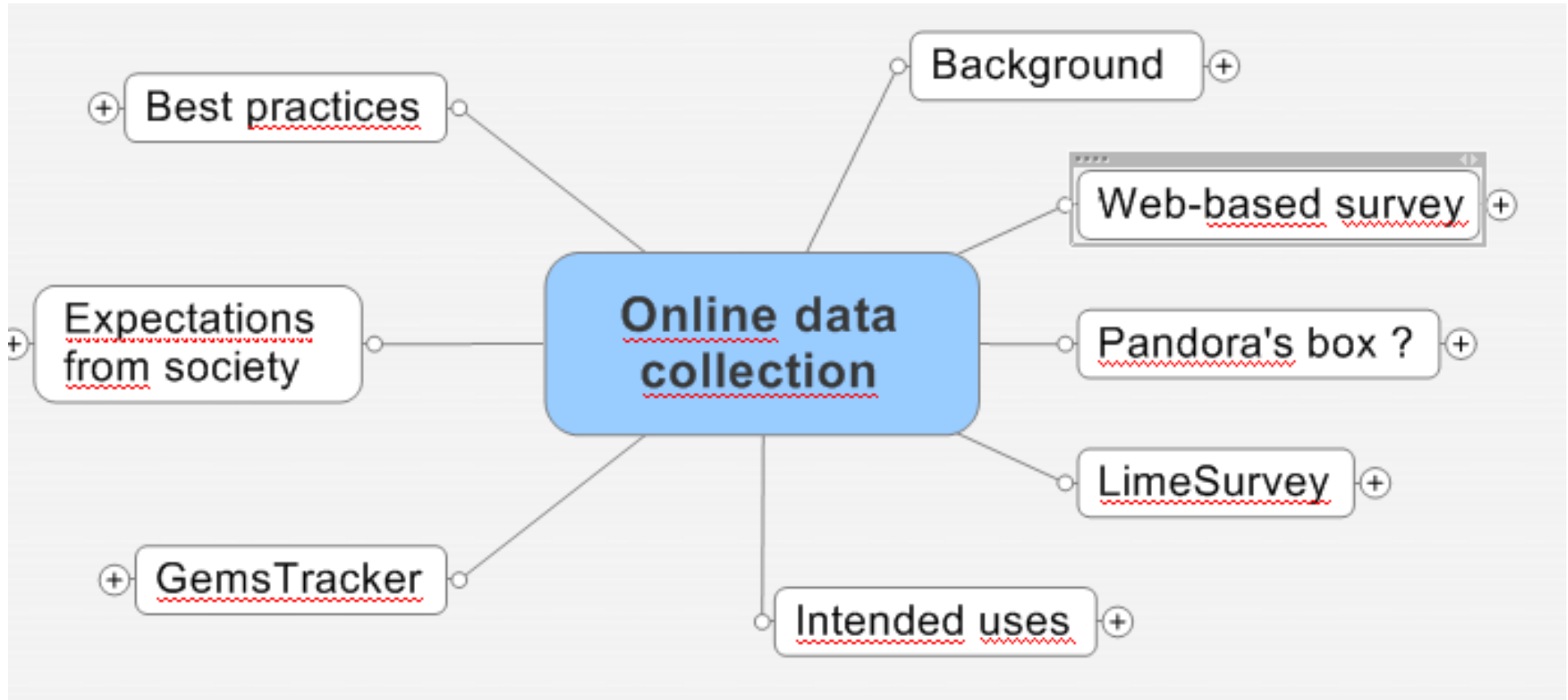


Online data collection



LimeSurvey

Web-based questionnaires or registrations

- User defines questions, variables, answers ...
- User does administration, sending ...
- Data-export to Excel, SPSS ...
- Anonymous and direct (e-mail, token).
- Open Source, popular, extensively tested.
- Development participation: extending functionality
- However the administration facilities are simple and it has not a functionally rich follow-up system

Intended use

- Administrative research scenario follow-up system, web-based, multiple organisations, multiple cohorts.

Other uses

- Benchmarking data.
- Quality control data.
- Protocol implementation.

GemsTracker

web-based registration follow-up system. High integration with a basic webbased survey system e.g. LimeSurvey.

- Open Source.
- Toolbox, modular, add-in. Consultancy for implementation.
- Security by design. Data.separation: Identity from data; organization; role/function. Logging. Communication: https and certificate ...
- Designed to be used in any (medical) care providing process. Relevant feedback on collected data.
- Team: data professionals, programmers, web designer, researchers, quality control manager.
- 8 year experience in on-line data collection

Society expects

e.g.:

- Secure data. Privacy maintained.
- Informed consent and other rules.
- Remove data on request. Access to personal records. Use data as communicated.
- Responsibility. Certify your reliability. Be open about incidents.
- Appropriate survey/registration burden on respondents.
- Open Data.

Best practices

Please use our own judgement
too

- Do not underestimate your on-line data collection process. Concepts may be simple. Reality is complex and far from predictable. Make your infrastructure needs explicit.
- For small teams: look for an experienced, reliable partner. For larger organizations: facilitate on-line datacollection. E.g. by a trial office that really helps.
- Compensate the limitations of the researcher role.
- Research is customized and innovative. It is likely that this impacts the requirements of the IT solution you intend to use.
- Security is often cumbersome, costly etc. Choose appropriate levels. And look for approval.
- Security cannot be bolted on afterwards.
 - Separate identifying data from the rest. Give only access rights according to the task, separate datadomains etc.
- Reward those who register in your system by providing relevant reports, to-do lists etc..
- Let's document how a proper on-line data collection infrastructure looks like.
- Do not mix with the EPD domain. Do your own thing and establish well secured and monitored communication canals.

Discussion

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Software links:

<http://www.limesurvey.org/>

<http://gemstracker.sourceforge.net>