careum

THIRD MEETING GRUNDTVIG LEARNING PARTNERSHIP Health literacy and health education fostering participation and improving women's and men's health

12th and 13th of November 2012, Zurich

MINUTES

Agenda

Monday	***November 12th 2012***
10.30-11.00	*Arriving and coffee*
11.00-11.10	Welcome
11.10-11.40	Objectives/expectations on 3rd meeting (Round the table discussion)
11.40-12.45	Interactive group activity 1: "Searching and evaluating health information" • Quick summary of a) potentials and challenges of (online) health information as well as b) web tools for patients/caregivers (websites, search engines) • Identifying/summarizing quality criteria for evaluating health information available on the web (including visualization, working framework)
12.45-13.45	*Lunch break (on site)*
13.45-15.15	Presentation Part 1: Best practice examples for improving health literacy with print and online information • Careum (including brief catch up of Copenhagen topic) • Istituto Superiore di Sanità Discussion and evaluation based on previously developed working framework
15.15-15.45	*Coffee break*
15.45-17.15	Presentation Part 2: Best practice examples for improving health literacy with print and online information • Women's Health Center Graz • Danish Committee for Health Education Discussion and evaluation based on previously developed working framework
17:15-17:30	*Bio break and refreshments*
17.30-18.30	Partnership topics (reporting experience, event reports, round-table-catch up), other matters and closing day 1
18.30-19.00	Walk to dinner location
19.00-21.30	*Dinner (location tbc)*

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Tuesday	**November 13th 2012**
08.45-09.00	*Arrival and coffee*
09.00-10.30	Group activity and discussion: "Searching information for guidelines development"
10.30-11.00	*Coffee break*
11.00-12.30	Group activities and continuing discussion, including further topics identified in 1st meeting part 1 (see meeting minutes Nov 2011, 4.4.3, p. 7)
12.30-13.30	*Lunch break (on site)*
13.30-15.00	Group activities and continuing discussion, including including further topics identified in 1st meeting part 1 (see meeting minutes Nov 2011, 4.4.3, p. 7)
15.00-15.30	*Bio break and refreshments*
15.30-17.00	Organizational topics and next steps (preparation of Rome meeting, dissemination of partnership experiences/findings)
17.00-18.00	Wrap up, closing thoughts and good bye

Monday, 12.11.12

Agenda changes for the 1st day:

- Information + HL
- Internet & Search Engines
- Quality Criteria for Evaluating Health Informations
- Searching Information for Guideline Development
- Web 2.0 Tools

Additional expectations for the meeting

- Christine: should there be extra time reserved for discussions (agreement on topics)? How to do this?
- Therese: the minutes from Copenhagen were very helpful. Besides, a common definition of health literacy is very important and partnership should come up with an own concept.
- Christine: mentions that in future meetings discussions should be summarized in the minutes; this could be used for an article about what we have learned and what are the results; the minutes should have more text and could also function as a public report.
- new topics, which come up in our work today can be considered as topics for tomorrow

Group activity 1: «Mini-Lab»

Input on method used – «mini lab»: Has been developed for tank ship crews when they have to cast anchor, a highly complex process building on trust. Mini lab is a sequential group activity based on specific answers that can be extremely useful if a group comes together for the first time. It can be also used in counseling or teaching as a tool to create trust and for getting people to know each other. It is highly structured and participants have to form groups, answer certain questions within a limited time frame. Instructions can be written down on a flip chart. Questions can start with easier ones like "A very nice experience I had recently?" or "A tough experience I had recently?" and then move on to more intimate ones like "How frankly am I in a group?" or "What are my worst fears?". Scaling questions can also be used. Instructors can summarize answers on a flip chart and use this as a visualization of the group process.

The mini-lab in the Grundtvig meeting was about
a) potentials and challenges of (online) health information
b) identifying/summarizing quality criteria for evaluating health information (web)

Answers of the groups on **usefulness of health information** were:

- reservoir of knowledge/information. example: food industry: healthy and tasty is not the same, but you can eat healthy *and* tasty
- information is important to make decisions. you need to know about different health issues
- useful for education
- transforming complicating topics in understandable messages
- recipients can get empowered, awareness, being able to compare possibilities, make better use of resources in health system, becoming an actor
- useful for producers
- information is useful if it is easy to understand and trustworthy
- needed for an equal basis between patient and expert
- to be able to act as a patient

Answers of the groups on **challenges of health information** were:

- changing recommendations in the health sector (things that are healthy today can be unhealthy tomorrow)
- who's behind the information, hidden agenda of producers (like pharma interests)
- information is not enough - need of legal framework (structural changes) for health information (like non-smoking in restaurants to push people to stop smoking).
- "nudging": put healthy food in specific areas in the supermarket, like fruits near the cashiers instead of candy (Nicolaj recommends the nudging newsletter www.inudgeyou.com)
- provoking demands by information (patients ask for drugs they saw in tv etc.)
- how to decide between high quality information and low quality information (consumers), differentiation
- general overload of information: insecurity, overload
- how to get from information to action?
- low level of information users have (basic health knowledge about anatomy etc.)

Answers of the groups on **web-tools** were:

- easy access (but not for everybody)
- update possibilities in Web-Tools are better (other than print)
- Challenge: who decides the top ten recommendations of Dr. Google? Who is delivering the information for the web? Hidden agenda as well, a lot of manipulation
- interactivity
- transparency: for example quality of hospitals like comments of former patients, reports by government,
- quality
- possibility of communication with people who downloaded Apps or visit a website (push-function)
- good Web tool: you have to know your target group very well, who has access to the web > differentiate between web tools: purpose, target group, access, possibilities

Answers of the groups on **reliability/relevance** were:

- the more basic the information the more relevant and understandable
- options/solutions > reliability
- who is the provider > reliability
- relevance always depends on the user
- evidence based
- HON-Code

- information can be relevant to raise awareness, but cannot be relevant to cause changing behavior/action
- depends on the stage of your disease or health status (prevention, treatment...)
- formal / content certifications of websites > reliability
- evaluation if the information reaches the users
- sex & gender: content relevant information (men & women, rich & poor etc.)

Presentation Part 1 (see ppt-presentations on SugarSync)

Careum on Evivo and dialog gesundheit health information:

- program is on providing information and support skills
- Evivo is active group education; emphasis is on goal setting combined with written and oral information
- role modeling leads to people being more active after the course
- one key principle is self-tailoring
- Evivo supplemental information (book) is both evidence- and experience-based
- Other health information and resources: Wie?So! is based on a license from Berkeley. Bringing together health information on a community basis suited to the needs of people in the community

(ISS on OKkio alla SALUTE:

- focus on childhood obesity
- "mind your health"
- example of best practice on improving health literacy with print and online information
- encourage people to ask questions and understand the answers

Discussion on the presentations included:

- What is the difference between health promotion and health literacy: campaign is to inform. Spots broadcasted in television during children programs. Spot is very expensive, paid by ministry of health. Lot of educational spots in Italy.
- What about the north/south-difference? Campaign is done in schools, north and south → so they receive the same information. Different strategies are not possible, because it is a national program.
- Social determinants are significant – well-educated people are always healthier → which intervening factors?
- Experience with TV spots in other countries? Austria uses few clips. Literature says: only effective if very target specific - broad campaigns normally aren't so effective. Big companies never do campaigns only on TV. Pharma industry does campaigns that work → lets copy this strategies!
- Italian campaign is not only on TV but in classes, at home, and delivered by teachers.
- In Denmark it wouldn’t work because there is only one slot in TV program where you can buy in
- provide spots on every social media channel, if TV is too expensive
- example TV: Denmark on first beautiful day, interview on TV -> everyone sees it, but not necessarily does changing habits

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Presentation Part 2 (see ppt-presentations on SugarSync)

Austrian health portal "gesundheit.gv.at":

- provided by government
- to empower people with information on diseases and healthy lifestyle
- transparency of health system

Women' Health Centre on health information brochures and online information:

- a lot of groups don't want the patients to be empowered too much (like pharma, insurances, patient lawyers etc.)
- challenges is also how to find high quality online information
- important: independent evidence based (if possible), understandable & list of criteria (see presentation on online information)
- method: workshop. discuss challenges, tools to evaluate information, present good websites. participants research in the workshop and ask questions.
- research report on reliable websites in Austria

Danish Committee on App "My Baby"

- for new parents
- topics on the new born baby
- put the name of the baby in -> personal
- Calendar for appointments (for vaccination)
- first aid for crying babies, diseases, sleep etc.
- can easily be translated in German or other languages
- planned next apps: pregnancy, action plan
- recommendations from the health ministry, no different information on the same topic

Discussion on the presentations included:

- development of interactivity is important because of the load of information
- netdoctor is a commercial website: much more visitors but more advertising. Health portal is new → shows the growing importance of health literacy and information in Austria
- who uses the health portal? Not yet known
- ELGA needs an access point → website with login
- how strong is the political influence? No topical influence but quality criteria of links (e.g. pharma sponsored websites) is controlled by ministry.
- in health information brochures the images have to fit the topic: gender, ethnics, age etc.
- to include user experience in the process of developing health information brochures could result in a lot of benefits
- online health information on the web better used by men?! (55 vs. 45%)
- workshop on online information: how can you disseminate information on a larger group of people? Basic information → put it on the national health portal?
- interactive version on the web could be interesting, not only displaying
- high quality = helping make a decision (experience based) → user involvement. information has to be relevant to user.
- non-commercial apps are considered more trustworthy: commercial apps stopped the development
- app development takes time: 9 month development
- apps bring with them the possibility to do a website version
- selling of books and written material decreases

Brainstorming on Health Apps (possible future topics):

- physical activity
- stress management
- medication management
- contraception

- nutrition
- screening app
- lifestyle of older people
- stop smoking
- weight management

Reflection on day 1:

- next meeting 11./12. april 2013: Italy sends a list of hotels soon
- time: 2 full days, starting time to discuss

Expectations for day 2:

- Organizational stuff first (9-10.30): partnership topics
- guideline development afterwards

Tuesday, 13.11.12

ISS on searching information for Guideline Development (SNLG-iss.it)(see SugarSync for further information)

- clinical guidelines for doctors and general public for specific topics
- step 1: organize a multidiscipline group: doctors, nurses, midwifes, patient associations, physiotherapists, etc.
- step 2: formulate questions
- step 3: research literature for answering these questions
- developing a guideline is very expensive: about 25000 euro
- take existing guidelines and adapt them, e.g. IGN (Scottish organization), repositories (useful to compare guidelines),
- search PubMed, Embase, and other specific databases for clinical trials, case studies: evaluators decide which are relevant
- evaluators read full text of relevant articles: grade the evidence on their reliability. if not possible, create a consensus conference
- versions for health professionals and leaflets for patients/general public
- problem: from guideline to practice
- problem: interests of different groups (e.g. psychotherapy was not recommended for autism: psychoanalysts were not amused), agreement must be found on the text; strong economic interests
- handbook online on the process of developing guidelines

Discussion included:

- patients should be represented in the boards by patient associations. In case of rare diseases or e.g. caesarian section: how are they found and how is decided who takes part? And are they represented in every board? Is it a standard procedure to include patients? What criteria is there? Are they trained to understand evidence? (in Italy there is no systematic training for patients on understanding evidence like in Austria).
- Christine: Good thing that all kinds of health professionals sit together and decide on a topic (there is no such thing in Austria). Joerg: However, without patients in the board a lot of things get lost
- in Switzerland there are expert driven and patient driven associations
- how is the public versions produced: prepared by a private agency (specialized). They use simple language, translate technical terms to Italian.
- how does the public versions affect patients? - no evidence. Discussion about caesarian section in the newspaper after the guidelines were published

- how are the guidelines used and observed? – implementation of guidelines is critical. guidelines only are a first step, but there is no follow-up-system → only recommendation.
- public version is a decision aid. Joerg: it exists an international standard on decision aids (quality criteria for patient centered health information and decision aids): ipdas.ohri.ca.
- Joerg shows www.bresdex.com with a tool to make a decision (e.g. on breast cancer). Decision aids in other countries: not known
- guidelines could be a high level health literacy - but how to get them used by health professionals?
- who finances the development of guidelines? - in Switzerland: initiatives of certain people or associations, not by the ministry of health. No interdisciplinary approaches.

Group activity: Role of private sector:
⇨ results see flip chart documentation (photos) on SugarSync

Tool and topic of group discussion:

- what did we learn on the topic → summary (what are the most central points):
- even doctors can be influenced by pharmacy: non-conclusive information is needed → simple answers do not work, we need multiple solutions (e.g. drugs are a simple solution)
- Need for funding by patient organizations!? – challenge: they often fight for their own disease and profile
- Importance of transparency (agenda of the information provider, financer)
- Mind shift in academia on bias publications (even public studies are not published because of "wrong" results (other than expected))
- Differentiate between different groups like patients, health professionals, public health, private sector
- Profound debate on disease mongering (ex. osteoporosis)what is a disease? Function and effects of calling something a disease
- Structure and strategies of pharmaceuticals industry and other players in the health care market (e.g. Diagnostic tests industry)
- Health Action International HAI

→ We take this into the next meeting: strategies

Short briefing on Nudging:
Analogy: Think of a menu card at the restaurant

- not changing prices
- not changing the portion
- it's the layout or pictures or words like "healthy" → people choose for them self
- Other examples: smaller plates on a buffet, change position of food in a supermarket, footprint on the ground to garbage bins, pictures in a stairway to make more people use the stairs instead of the elevator
- Challenge: Is this manipulation?

Group activity Learning Process:
see Flipcharts pictures on SugarSync!

Partnership & organizational topics

Meeting in Rome:

11.4.13: 9-16 working sessions, 16- Open end: dinner and guided tour,
12.4.13: 9-17 working session

Topics:

1. If possible, input on national strategies from WHO (Agis Tsouros) and UK (Jim Phillips: if he can give insight on practical work) → Jörg asks Jim (1), Charan asks Agis (2)
2. How to develop a national strategy? steps, stakeholders, experiences
3. Common (future) goals? Joint proposal/grant application?
4. Evaluation (chaired by Christine Hirtl)

- Draft Agenda: Italy prepares the agenda (draft), all partners send comments
- Main facilitator: Italy
- Organization: Italy
- Final report: Draft, input of all participants

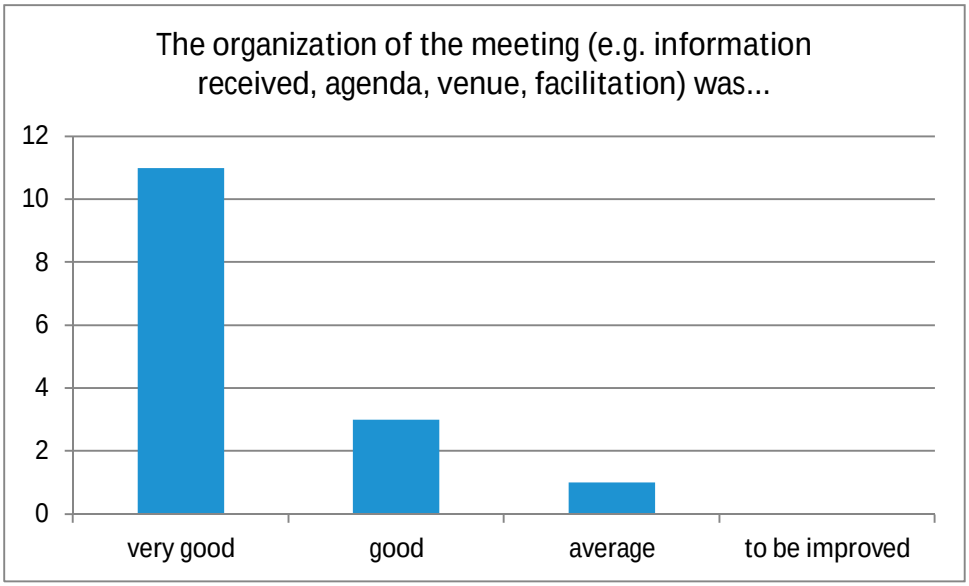
Dissemination of results:

- Send to colleagues, partners, stakeholders.
- Publish the final report on each partner's website.
- Spread results in other networks (ENOPE, womens network, libraries), european treasure database.
- Anyone can write an article: send it to the others in advance.
- Map of methods: Maurella.
- information on the web: every organization should put information online about grundtvig
- results we make public: minutes, final report, poster (italy) on every website

EVALUATION 3rd MEETING

A total 15 participants filled in the evaluation form.

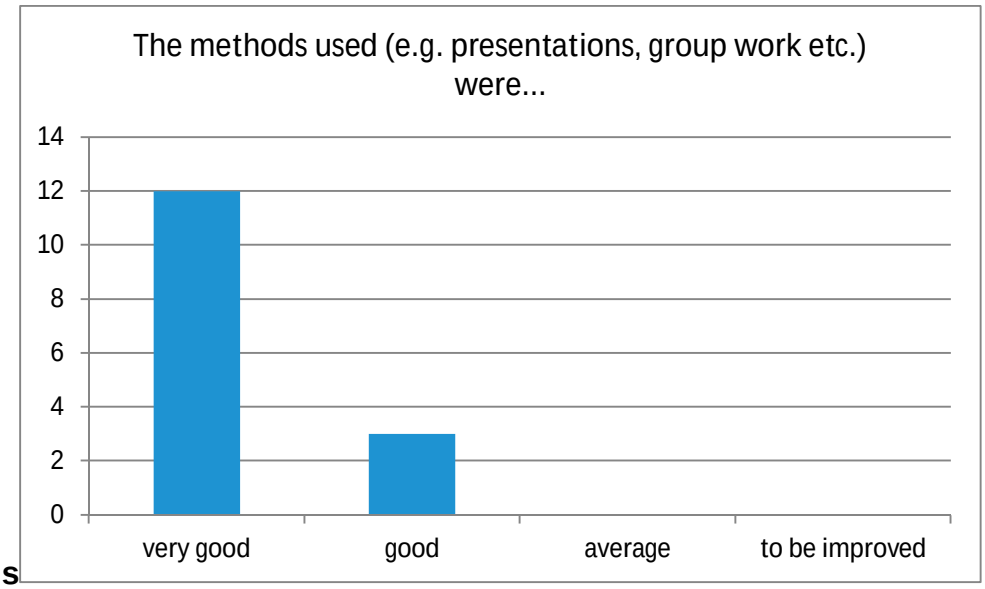
1. Organization



Free comments[1]

- Apparently I didn't realize all the information where I could have reacted
- Everything very well organized
- Kind hospitality
- Excellent method
- Everything perfect
- Could not have been better
- Great food the 1st day – lost 2 kilos Thank you ☺
- Everything was perfect
- The agenda was very long and full of contents but the facilitation was so good that we could cover all topics included
- Role of facilitator wasn't clear after Copenhagen meeting; created uncertainty at beginning of meeting
- Lunch break day 1 wasn't running smoothly
- Information and agenda was sent out early enough
- Nice location
- Fruits, water and coffee
- Lunch 1st day: not so healthy

[1] The number in brackets indicates the number of participants who did this comment

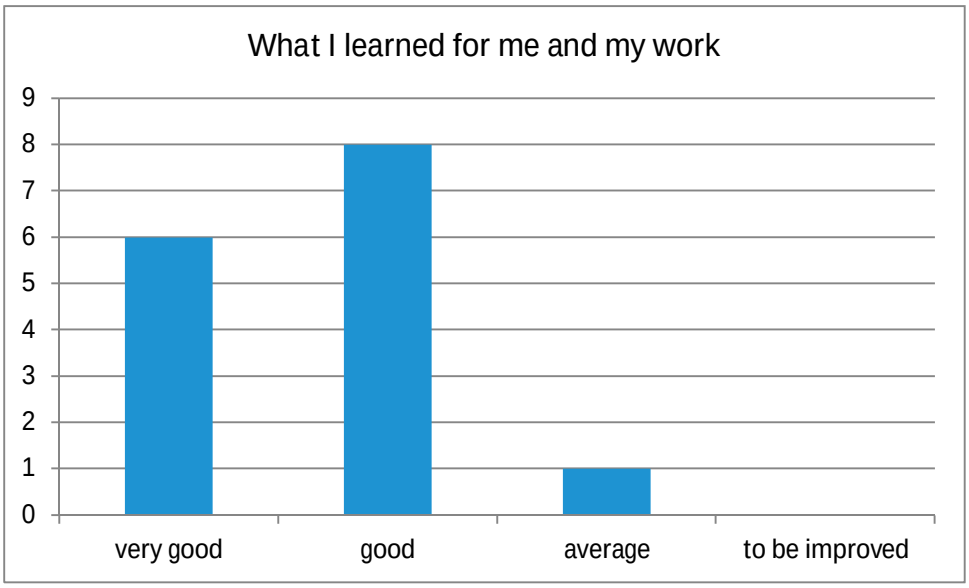


2. Methods

Free comments

- Mini Lab (5)
- Presentations
- Discussions (3)
- Take a stand (4) (sollte methodisch strikter durchgezogen werden)
- Mix of different methods (each method has limits), but as a whole it fosters good debates
- Presentations should be accompanied by documents
- Variety of methods (5)
- Broad participation
- But there is a great challenge in facilitating meetings in English, when ¼ of the partnership speaks poorly English. This means that it is limited, what methods you can use.
- I enjoyed presentations and the mini labs. I had some difficulties in following the take a stand discussion on private contribution to health information.
- Group activities facilitated discussions
- Methods/things I found difficult:
    - Questions should/could be focussed a little bit more
    - That group activities tended to scratch surface sometimes

3. Learnings

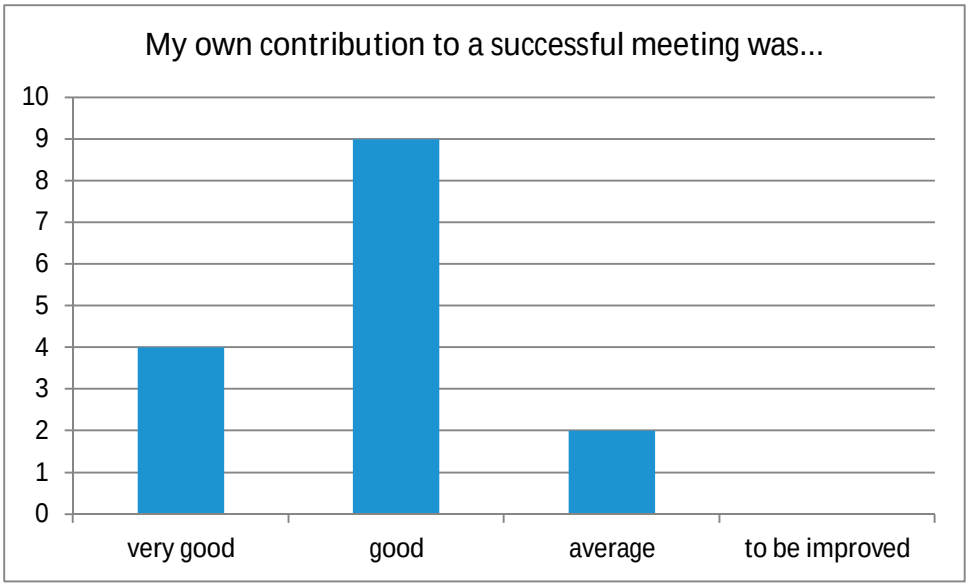


Free comments

- Health and health literacy are not yet evidence-based!
- The learning potential is very high
- The insight in gender and cultural specific settings are of great importance
- Various methods and experiences
- Various points of view to evaluate the models
- Step back and listen carefully to the experiences of the others
- Different systems in different countries
- New form of mobiling information: App, campaign
- Status of health information in other countries
- Challenges of stakeholder
- Role of pharmaceutical industry to influence the public and politicians
- Tool on HL: to transfer to Austria
- Methods for moderate/facilitate
- To learn from other countries is always beneficial
- New app to be translated in many languages
- Different methods for learning strategies
- Dissemination of information in Austria through a national portal
- Lots of examples and inputs for future project activities
- App - idea/project for own projects
- Importance of patient engagement
- How to prepare guidelines
- Neues Wissen über HL & HP

- Strategien von Präsentation
- Wissen furs Networking

4. Contribution



Free comments

- I represent the Swiss situation which Is not making a form position (but participating with a rather loud voice)
- As a newcomer, I was not much prepared to bring consistant inputs. But the quality of the discussions has permitted me to bring some important points
- Facilitation
- Contribution in discussion
- Preparing the partnership session
- Point of views on special topics
- Sharing experience
- Maybe I was a bit dominating, but sometimes it is necessary to get things started, when the language skills vary
- Tried to do my best
- Dealing with variety of topics and uncertainty of facilitating the meeting was challenging but interesting
- Writing minutes
- Take part in discussions

Further comments

- The lunch wasn't a problem!
- The sessions were perfectly moderated
- Look forward on the next meeting and the final report
- It is our best meeting up to now. The group is getting closer and closer
- Great learning opportunity and exchange of knowledge
- Thank you for the wonderful dinner at the Rosengarten restaurant

Zurich, Nov 23rd and Dec 19th 2012/cn, jh