Future collaborations between healthcare, industry and patients for faster and better results

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Future collaborations between healthcare, industry and patients for faster and better results

I. EFCNI works on a multi-stakeholder approach

II. The needs and challenges

III. Working on two different planets?

IV. What has to be done?
Working together – a multi-stakeholder approach

- Policy makers
- Parent Organisations
- Industry
- Third parties
- Media/Marketing
- Professionals
Parental involvement is more and more demanded

• Clear need for more and better drug/nutrition/follow-up studies in children – supported by patients and families

• Examples show invaluable input of patients and families at ALL stages of a research project but still, a lot of questions remain:

  • *How to involve parents/patients in the development of relevant outcome measures?*

  • *Recruitment strategies (what information, by whom, how, timing)*

  • *Ethical issues in relation to topics like involvement of families till data- and biobanking*
Valuable and equal partner of research projects

- Driving force behind clinical trials
- Co-research partner with international network to parent representatives
- Reviewer
- Advisor (“expert by experience”)
- Information provider
- Research object
- Ethical aspects
- Network to target group(s) and multipliers
- Building bridges and promotion of project
- Network helping to put research into practice
Some critical thoughts by parents…

• “In my case, I missed certain follow-up afterwards, a minimum of information in order to know if our contribution was useful, if any conclusions were obtained. Obviously, most results are to be seen at long-term, but receiving a piece of information would have made us feel recognised and valued.”

• “We trusted them and agreed to participate - at the end, we just felt like being good for delivering data, but not being recognised as a family with our own background and needs.”

• “I have to take my child to 18 appointments per month, not including physiotherapy… 250 appointments per year. A research project adds to this – I cannot manage still another appointment and my daughter cannot afford missing again another day at school.”
Being an equal partner?

"IT'S ALL RIGHT - HE CAN'T READ."

"I'M WITH STUPID"
Research and parental/patient involvement
- Two different planets?

**Researcher/Investigator/Industry**
- Interesting questions
- Good data, data analysis, evidence
- Publications
- Solution in the future

**Patient/Parents**
- Emotions, trauma
- Coping with daily life
  - Worries (child, family, ...)
  - Organisational challenges
- Direct solution for child/ family
First Step
How did Parent Organisations experience research involvement in the past?

Limited involvement of Parent Organisations

- Mainly - letters of support
- Rarely - participation in phone calls; reading material

Often overwhelming

- Last-minute requests
- Nearly no background information or
- Mailing of extensive research documents in scientific language

Often feeling of „inequality“ and „exploitation“

- Missing recognition or acknowledgement
- Barely feedback on success of application or next steps
- Barely information on project outcome
- Barely outreach to „end user“, other target groups
Healthcare research at a turning point

- Increased patient empowerment: Awareness of own values and capacities; better understanding of opportunities through collaboration

- Increasing awareness of importance to include “user perspective” to improve research quality

- Patient centred research carried out “with” patients rather than “to” or “for” them

- Involvement of Parent Organisations requested by grant giving bodies as of 2015
Involving patient representatives in research
New challenges to manage

- Flood of research application requests
- Last minute consultation requiring rapid responses
- „Involvement“ of patient representatives not defined
- Missing clarity of new roles
- Not taking seriously this new way of collaboration
- Refusal of participation can be challenging and create pressure
- Few practical experiences to learn from

Change in traditional research-clinician-patient relationship:
from advice seeker to colleague whose point of views should be considered seriously
Working together and learn from each other

Learning from each other’s worlds
What do patient representatives need?

- Access to terminology
- Understanding how research works, how to read, interpret studies, how to become co-applicants for grants (targeted training!)
- Access to full information e.g. e-mail exchange or „corridor meetings“
- Access to positive facts as well as risks involved
- Access to (steering group) meetings
- Access to resources (payment and funding)
- Self-confidence to speak up in expert rounds or panels and to stakeholders
Principles to guide meaningful collaboration (I)

- Longterm collaboration and continued partnership
- Honesty and transparency (information including positive facts and risks)
- Independency
- Security and clear expectations (confidential agreement; codes; compensation)

Fair partnership on equal footing
Principles to guide meaningful collaboration (II)

Communication and dialogue

Facilitate communication (level, language)

Acknowledgement and valuing of contributions
Principles to guide meaningful collaboration (III)

Capacity building

PATIENT
Research and R&D
Scientific language
Interaction with stakeholders

RESEARCH TEAMS
Understand parental concerns
Understand benefits for research
Interaction with patients
Position Paper: Giving patient representatives a voice

Carrying the different pieces together:

• EFCNI’s own experiences of the past years
• Incoming requests for advice by Parent Organisations
• EFCNI’s exchange and discussion with Parent Organisations
• Debates with EFCNI Parent Advisory Board

Findings:

• Similar challenges, gaps and needs in different countries and settings
• Patient representatives need to speak up for themselves, to accelerate a mind change

Position Paper:
How parents would wish to be included as representatives in research, highlighting challenges and possible solutions
We need more research in the area of maternal and newborn health

It is time to act and combine forces, now!
EFCNI example: drug trial / neonatal seizures (industry funded)

- Advising on
  - Useful patient information, material, formats
  - Patient-friendliness of information material e.g. consent form, flyers, patient brochure, website content, overall „look-and-feel“
  - Patient needs and „real-life challenges“
  - Building the bridge patient/ professional
  - Communication with patients during different project phases e.g. recruitment; follow-up
- Identifying and establishing parental advisory board according to project focus and needs
- Coordinating parental advisory board (e.g. NDA, honorarium, contract, questionnaires, comment phases, feedback analysis)
Role of EFCNI in SHIPS – an EU funded project
Some impressions